# Understanding advanced (metastatic) prostate cancer

# About this booklet

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

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

This booklet does not have information about diagnosing prostate cancer, or about early (localised) or locally advanced prostate cancer.

We have other booklets called:

- Having tests for prostate cancer (PDF only)
- Understanding early (localised) prostate cancer
- Understanding locally advanced prostate cancer.

This booklet is also available as an audiobook. Visit macmillan.org.uk/audiobooks or call 0808 808 00 00.

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

## How to use this booklet

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

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

On pages 150 to 160, there are details of other organisations that can help.

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

## Quotes

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

## For more information

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

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

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

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

# Contents

# The prostate and cancer

# What is cancer?

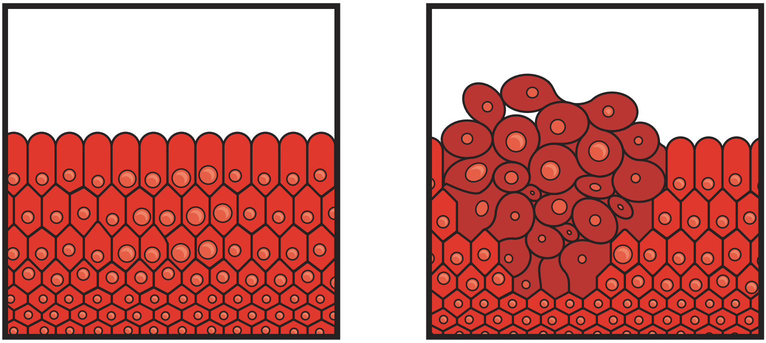
Our bodies are made up of tiny building blocks called cells. Inside every cell is a set of genes. Genes are the instructions the cell needs to work properly.

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

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

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

## Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample to look for cancer cells. This is called a biopsy. We have more information about biopsies on our website. Visit macmillan.org.uk/biopsy

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

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

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

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

# The prostate

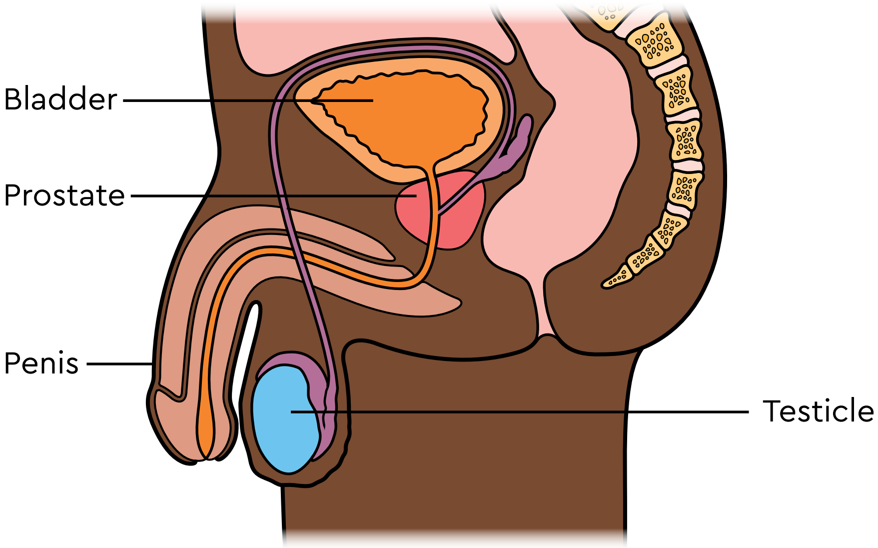
The prostate is a small gland about the size of a walnut. It is divided into 2 lobes and surrounded by an outer layer called the capsule. The prostate naturally gets bigger as you get older.

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

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

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

## The prostate



# What does the prostate do?

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

The hormone testosterone controls how the prostate works. Testosterone is mainly made by the testicles. It is responsible for many things such as your sex drive (libido), getting an erection, muscle development and heart health. It also makes you feel more energetic and helps keep your muscles and bones healthy.

The prostate also produces a protein called prostate-specific antigen (PSA). This helps to make semen more watery. Some PSA leaks into the blood. A PSA test measures the levels of PSA protein in the blood. We have more information about the PSA test on our website. Visit macmillan.org.uk/psa-test

Doctors use this test to help diagnose different prostate problems, including prostate cancer.

It is not only prostate cancer that causes a raised PSA level. Other prostate problems, such as an enlarged prostate, can raise it. An enlarged prostate is called benign prostatic hyperplasia (BPH).

Infection or energetic exercise can also raise the PSA level for a short while.

> "I had a health check and although the rectum examination came back normal, my PSA level was slightly raised. This led to a discussion with my GP and eventually to a digital rectal exam that showed an abnormality. She referred me to a urologist."

Elvin, diagnosed with prostate cancer

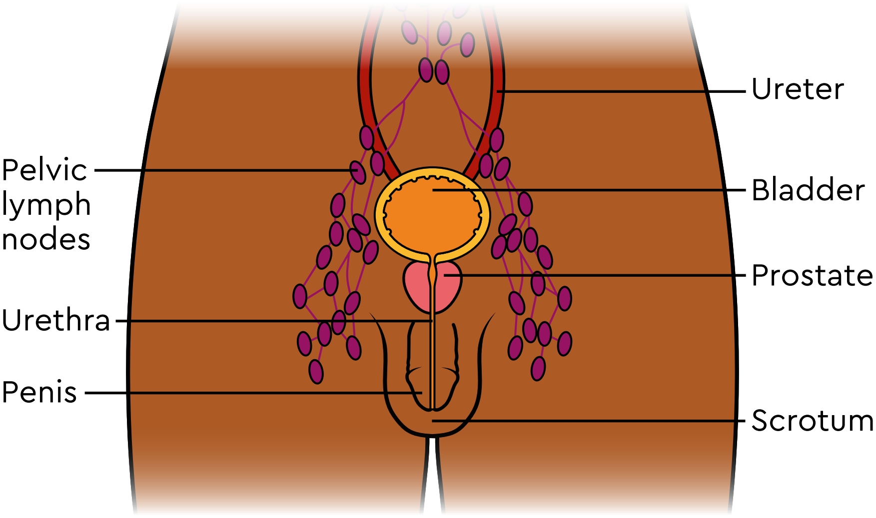
# The lymphatic system

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.

In advanced prostate cancer, there are usually cancer cells in lymph nodes close to the prostate and in lymph nodes further away.

## Prostate lymph nodes



# Prostate cancer

Prostate cancer is one of the most common cancers in the UK. It is more common over the age of 65. Although it can happen at a younger age, it is uncommon under the age of 50.

There is a higher risk of getting prostate cancer at a younger age if you are Black or have a strong family history of prostate cancer. The risk can also be higher if you have a family history of breast or ovarian cancer.

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

Prostate Cancer UK has detailed information about trans women and prostate cancer. The LGBT Foundation can also give you confidential advice and support. OUTpatients is a charity that supports LGBTQ+ people who have been diagnosed with cancer.

# Types of prostate cancer

There are different types of prostate cancer. This booklet is about advanced prostate cancer. Advanced prostate cancer can also be called metastatic prostate cancer. In this information we use the term advanced prostate cancer.

## Early (localised) prostate cancer

When prostate cancer is only in the prostate gland, it is called early or localised prostate cancer.

We have separate information about this in our booklet Understanding early (localised) prostate cancer.

## Locally advanced prostate cancer

If the cancer cells have spread outside the prostate gland to nearby areas, it is called locally advanced prostate cancer.

We have separate information about this in our booklet Understanding locally advanced prostate cancer.

## Advanced (metastatic) prostate cancer

Advanced prostate cancer is when the cancer cells have spread from the prostate gland and very nearby area to other parts of the body.

The cancer cells spread through the blood or through the lymphatic system. When the cancer cells reach a new area of the body, they start growing in that area.

The most common places for prostate cancer to spread to are the lymph nodes and the bones. It can also spread to other organs, such as the liver or lungs. Even if it spreads to other parts of the body, it is still prostate cancer.

Sometimes, prostate cancer is advanced when it is first diagnosed. Some people are diagnosed with advanced prostate cancer after having treatment to cure early or locally advanced prostate cancer. This can happen because at the time of their treatment, it was not possible to detect the cancer cells that were present outside the prostate gland.

It is not possible to cure advanced prostate cancer, but there are treatments that can help to control it and slow it down. These treatments can also help with symptoms and your quality of life.

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

# Planning your treatment

# Finding out you have advanced (metastatic) prostate cancer

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

This information is written for people who have already been diagnosed with prostate cancer. We have more information about possible causes, risk factors and symptoms of prostate cancer and information about tests for prostate cancer on our website. We also have a booklet called Having tests for prostate cancer, which is available as a PDF.

This booklet is about advanced (metastatic) prostate cancer. We have separate booklets about Understanding early (localised) prostate cancer and Understanding locally advanced prostate cancer.

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

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

> **"Macmillan gave me a proper boost after my cancer diagnosis. You knew you had someone there you could speak to about anything – money worries, getting to and from appointments, and a huge list of other support."**
>
> John, diagnosed with prostate cancer

# Staging prostate cancer

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. You and your doctors can then talk about the best treatment choices for you.

Your doctors also look at the grade of the cancer to help them plan your treatment. The grade gives an idea of how quickly the cancer might grow or spread. Doctors often use the TNM staging system or a number staging system for prostate cancer.

## TNM staging

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.
- **T3** tumours have spread outside the prostate and may be growing into tissues or organs close by.
- **T4** tumours have spread into areas close by, such as the bladder or back passage (rectum), or the muscle that controls peeing (passing urine).

## 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.

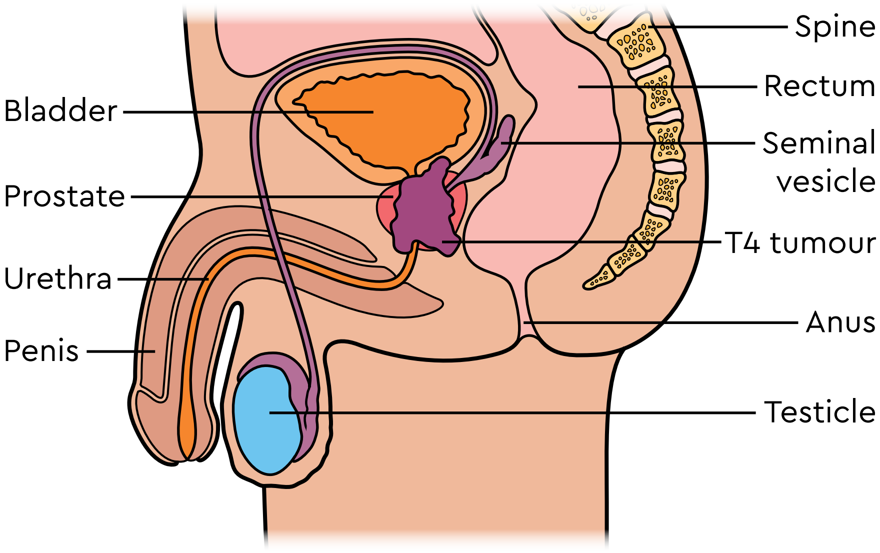
## Metastasis

- **M1** means the cancer has spread to another part of the body.

With the TNM staging system, advanced (metastatic) prostate cancer can be any **T**, any **N**, but will always be **M1**.

You can talk to your urologist, cancer doctor or clinical nurse specialist (CNS) about your TNM staging. They can explain it to you.

## T4 prostate cancer



# Number staging system

Number staging brings together different parts of the TNM staging system and gives it a number stage. Advanced prostate cancer is always stage 4. But some stage 4 cancers are locally advanced.

Stage 4 can be either of the following:

- A **T4** tumour that has not spread to the lymph nodes close by, or any tumour that has spread to these nodes. Doctors call this locally advanced prostate cancer.
- Any tumour that may be in the lymph nodes close by and has spread to another part of the body, such as the bones, lymph nodes outside the pelvis, liver or lungs. Doctors call this advanced or metastatic prostate cancer.

We have separate information about locally advanced prostate cancer in our booklet Understanding locally advanced prostate cancer and on our website. Visit macmillan.org.uk/locally-advanced-prostate-cancer

# Grading prostate cancer

A doctor decides the grade of the cancer by how the cancer cells look under the microscope. The grade gives an idea of how quickly the cancer might grow or spread.

## Gleason score

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

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

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

- the most common grade
- the highest grade.

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

Most people with advanced (metastatic) prostate cancer have a high Gleason score. But it is possible for prostate cancer with a low Gleason score to spread to other parts of the body. A high Gleason score does not always mean the cancer is advanced.

# Grade Group

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

- Group 1 – Gleason score 6 (3+3). The cancer cells look very similar to normal cells and are likely to grow very slowly, if at all.
- Group 2 – Gleason score 7 (3+4). Most of the cancer cells look like they will grow very slowly. Some may grow at a moderate rate.
- Group 3 – Gleason score 7 (4+3). Most of the cancer cells look like they will grow at a moderate rate. Some may grow very slowly.
- Group 4 – Gleason score 8 (3+5, 4+4, 5+3). The cancer cells look like they will grow at a moderately fast rate. Some may look as though they will grow quickly.
- Group 5 – Gleason scores 9 (4+5, 5+4) and 10 (5+5). The cancer cells look like they will grow moderately quickly or quickly.

# Your data and the cancer registry

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

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

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

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

# Treatment overview

When prostate cancer has spread to other parts of the body, such as the bones, it cannot be cured. But you can still have treatments that will help. Treatments for advanced (metastatic) prostate cancer may control the cancer, sometimes for many years. Treatments can also help relieve any symptoms caused by the cancer and improve your quality of life.

Your cancer team will help you to understand the treatments and how they may affect you. It is a good idea to have someone with you at the appointment. They can help you remember what was said and you can talk with them about it afterwards.

The main treatments for advanced prostate cancer are hormonal therapy, chemotherapy, radiotherapy and radioisotope therapy. You may have a combination of these. Your cancer team will explain which treatments may be helpful for you. This will depend on:

- your general health
- where the prostate cancer has spread to
- your symptoms
- any previous prostate cancer treatments you have had
- how treatments and their side effects may affect your everyday life.

Your cancer team will help you decide on the right treatment plan for you.

# Hormonal therapy

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

Hormonal therapy is usually recommended for everyone with advanced prostate cancer. Most people start hormonal therapy to reduce the amount of testosterone. This is called androgen deprivation therapy (ADT).

You may have more than 1 type of hormonal therapy. You may also have hormonal therapy in combination with chemotherapy or radiotherapy.

# Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It may be given in combination with hormonal therapy when you are first diagnosed with advanced prostate cancer.

Chemotherapy can also be given when hormonal therapy alone is no longer working.

# Radiotherapy

Radiotherapy uses high-energy rays to treat cancer. It destroys cancer cells in the area where it is given. Radiotherapy can be given in different situations to treat advanced prostate cancer. You may have it in combination with hormonal therapy.

If you have been newly diagnosed with advanced prostate cancer, your cancer team might talk to you about radiotherapy to the prostate gland. Research has shown that treating the prostate can help with symptoms, even when the cancer has spread to other areas. It can help some people live longer. But radiotherapy to the prostate is not suitable for everyone.

You may have radiotherapy to help with symptoms, such as pain in the bones or prostate area.

# Radioisotope therapy

Your cancer team may also talk to you about radioisotope therapy. Radioisotope therapy can be used to treat prostate cancer that has spread to the bones. You may be given a radioisotope if hormonal therapy (ADT) is no longer helping to control prostate cancer in the bones.

# Targeted therapy

A type of targeted therapy called a PARP inhibitor can be used to treat advanced prostate cancer. You do not usually have it if you have been newly diagnosed with advanced prostate cancer. It is usually given when hormonal therapy is no longer working.

PARP inhibitors block a protein called PARP which helps damaged cells to repair themselves. Without the PARP protein, the cancer cells may become too damaged to survive.

You may have a PARP inhibitor called olaparib (Lynparza®). It may be used when tests show the cancer cells have a change in the BRCA genes (BRCA1 or BRCA2).

Some people have olaparib with a hormonal therapy called abiraterone.

Researchers are doing clinical trials for other PARP inhibitor drugs.

We have more information about olaparib and abiraterone on our website. Visit macmillan.org.uk/treatments-and-drugs

## Surgery

Surgery can sometimes help with symptoms of advanced prostate cancer. If you are having problems with passing urine (peeing), you may have an operation called a transurethral resection of the prostate (TURP). Surgery can also be used to stabilise a bone that is at high risk of a fracture.

You may have surgery to help control prostate cancer. The surgery involves removing part of the testicles to reduce the amount of testosterone naturally produced by the body. This is called a subcapsular orchidectomy. It is not reversible. This surgery is now rarely done. Most people have hormonal therapy to reduce testosterone instead.

Surgery to remove the prostate gland is called a radical prostatectomy. It is not used to treat advanced prostate cancer. This is because it cannot cure prostate cancer once the cancer cells have spread outside the prostate and nearby area.

# Supportive treatments

Supportive treatments aim to relieve and control any symptoms you may have. Supportive treatment is sometime called palliative care.

Specialist nurses called palliative care nurses provide this type of care. They are experienced in assessing and treating symptoms of advanced cancer. You may meet them when you are at a clinic or in hospital. Palliative care nurses also work outside the hospital, as part of a community palliative care team. Your cancer team may refer you to a community team even if you do not need help with symptoms. This will mean you have support if you need it.

There is also support available to help you cope with the emotional effects of cancer and its treatment. Your cancer doctor or GP may be able to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists can also tell you more about support services and counselling in your area.

Our booklets How are you feeling? The emotional effects of cancer and Coping with advanced cancer may also help. You can order these at orders.macmillan.org.uk or by calling 0800 808 00 00.

# Clinical trials – research

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

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

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

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

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

## Taking part in a clinical trial

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

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

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

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

Clinical trials are designed with safety measures to keep any risks to you as low as possible.

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

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

> **"I had the usual treatment of injections, and was then accepted on a clinical trial."**
>
> Tim, diagnosed with advanced prostate cancer

# 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:

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

The MDT may also include:

- a pathway co-ordinator – someone who can provide information and guidance for other needs such as financial support
- a therapeutic radiographer – someone who plans and gives radiotherapy, and supports people during radiotherapy treatment
- a palliative care doctor – a doctor who helps with symptom control and end of life care
- a dietitian
- a physiotherapist
- an occupational therapist (OT)
- a psychologist or counsellor.

You may meet nurses described as Macmillan nurse specialists. Macmillan nurses can be used to describe different roles such as CNS or palliative care nurses. We have more information about this on our website. Visit macmillan.org.uk/macmillan-nurses

The term multidisciplinary team applies to a range of professionals involved in your care. It can include professionals outside of the specialist cancer team. This includes medical and nursing staff on the wards or in different departments.

# Talking about your treatment plan

After the MDT meeting, you will usually see your cancer doctor and specialist 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 cancer doctor should explain:

- the aim of the treatment
- 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 1 meeting with your doctor or nurse to talk about your treatment plan.

## Benefits and disadvantages of treatments

It is important to know the benefits, possible disadvantages and side effects of treatments before you decide to have them. Your doctor or specialist nurse will explain these to you.

Treatments can help to control the cancer and relieve the symptoms. But there may be a time when the treatment has little effect on the cancer and you have the side effects without any benefits.

Making decisions in these situations is always difficult. You may want to talk about it with your cancer doctor, specialist nurse and family. It may also help to discuss the options with our cancer support specialists on 0808 808 00 00.

If you decide not to have further treatment, you will be given supportive (palliative) care, with medicines to control any symptoms.

## Making treatment decisions

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

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, following tests and scans.

# Giving your permission (consent)

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

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

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

## Second opinion

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

If you still want a second opinion, you can ask your 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 second opinions on our website. Visit macmillan.org.uk/second-opinion

# Hormonal therapy

# Hormonal therapy for advanced (metastatic) prostate cancer

Hormonal therapy is the main treatment for advanced (metastatic) prostate cancer. It aims to help control the cancer. It can shrink the cancer and reduce symptoms.

Your cancer doctor or specialist nurse will talk to you about the type of hormonal therapy that is suitable for you. They will explain the different side effects and things that can help manage them.

Prostate cancer needs the hormone testosterone to grow. This is mainly made by the testicles. Small amounts are made by the adrenal glands, above each kidney, and in the body fat. Some hormonal therapy drugs for prostate cancer reduce the amount of testosterone naturally produced in the body. Others stop testosterone from reaching the prostate cancer cells.

Testosterone is important for:

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

Hormonal therapy to reduce testosterone affects some of these things.

Your cancer doctor or specialist nurse will check how well your hormonal therapy is working. They will ask about your symptoms, examine you and monitor your PSA level. Measuring your PSA level is usually a good guide to how well treatment is working. If your PSA level rises, your cancer team may talk to you about having additional treatment.

## Surgery to reduce testosterone

Rarely, some people have surgery instead of hormonal therapy to reduce the amount of testosterone naturally produced by the body.

# Having hormonal therapy

Before you start hormonal therapy, you will have some blood tests. This includes a PSA test. Your doctor will also examine you and ask about your symptoms.

You may have hormonal therapy in the following ways:

- injections
- implants
- a nasal spray
- tablets.

You may have more than 1 type of hormonal therapy. You may have hormonal therapy with chemotherapy or radiotherapy when you are first diagnosed with advanced (metastatic) prostate cancer.

These additional treatments can be more effective than hormonal therapy on its own. But there are more side effects to cope with. Your cancer team can tell you more about this.

# Androgen deprivation therapy (ADT)

Hormonal therapy is usually given continuously to treat advanced prostate cancer. This is called androgen deprivation therapy (ADT).

ADT works by reducing the amount of testosterone the body produces naturally.

There are 2 types of ADT:

- luteinising hormone-releasing hormone (LHRH) agonists
- gonadotropin-releasing hormone (GnRH) antagonists.

They work by blocking the message from the brain that tells your testicles to make testosterone.

If you are having ADT as an injection or implant, the nurse at your GP practice can give it to you. Your cancer doctor or specialist nurse will tell them when to start treatment.

## LHRH agonists

LHRH agonists are the most common type of ADT. You usually have them as an implant or an injection under the skin (subcutaneously).

The drug buserelin is given as a subcutaneous injections for 1 week, and then as daily doses of nasal spray.

The commonly used LHRH agonists are:

- buserelin (Suprefact®) – taken daily
- goserelin (Zoladex®, Zoladex LA®) – given as an injection every 4 or 12 weeks
- leuprorelin (Prostap®, Staladex®) – given as an injection every 4 or 12 weeks
- triptorelin (Decapeptyl®, Gonapeptyl®) – given as an injection every 4 weeks, 3 months or 6 months.

### Tumour flare

The first time you have an LHRH agonist, your testosterone levels may go up for a very short time. This could make any symptoms caused by the prostate cancer temporarily worse. This is sometimes called tumour flare. To help prevent tumour flare, your cancer doctor will give you anti-androgen tablets to take for a short time before and after starting the LHRH agonist. Your doctor, nurse or pharmacist will explain more about this.

## GnRH antagonists

GnRH antagonists work quicker than LHRH agonists and do not cause tumour flare.

You usually have GnRH antagonists if the cancer has spread to the spine and there is a risk it could press on the spinal cord. This is called metastatic spinal cord compression (MSCC).

You may also have GnRH antagonists if you are at risk of a bone fracture or blockage in the kidney or ureter, or if you have other health conditions.

GnRH antagonists include degarelix (Firmagon®) and relugolix (Orgovyx®). You have degarelix as an injection under the skin of the tummy (subcutaneously) once a month. You take relugolix as tablets.

You may switch from degarelix to an LHRH agonist. This is because you can have LHRH agonists less often than degarelix. Your cancer doctor or specialist nurse can talk to you about this.

We have more information about these LHRH agonists and GnRH antagonists on our website. Visit macmillan.org.uk/treatments-and-drugs

# Intermittent hormonal therapy

Hormonal therapy is usually given continuously to treat advanced or metastatic prostate cancer. But if side effects are difficult to cope with, you may have a break from hormonal therapy before starting it again. This is called intermittent hormonal therapy.

Intermittent hormonal therapy is not suitable for everyone. It may not control the cancer as well as continuous hormonal therapy.

Your cancer doctor or specialist nurse can explain the possible benefits and disadvantages of intermittent hormonal therapy. You will have regular PSA tests during intermittent hormonal therapy. If your PSA level goes up or your symptoms get worse, your cancer doctor or specialist nurse will advise starting hormonal therapy again or having continuous treatment with androgen deprivation therapy (ADT).

# Other types of hormonal therapy

## Anti-androgen drugs

These drugs stop testosterone from reaching the cancer cells. You take them as tablets. You may have them:

- for 1 to 2 weeks before and after starting an LHRH agonist, to prevent symptoms getting temporarily worse (tumour flare).
- on their own as part of intermittent hormonal therapy
- with other hormonal therapy drugs (ADT) as part of combined hormonal therapy.

Taking an anti-androgen on its own as part of intermittent hormonal therapy may:

- have less impact on your sex drive (libido) and erections than other hormonal therapy drugs
- help avoid the side effects of combined hormonal therapy
- help reduce the risk of long term effects of hormonal therapy, such as bone thinning or increased risk of heart disease.

But anti-androgens alone may not control the cancer as well as other hormonal therapy drugs in some situations.

Anti-androgens include:

- bicalutamide
- cyproterone acetate (Cyprostat®)
- flutamide.

If you have been taking an anti-androgen drug for some months or years, and the cancer begins to grow, your cancer doctor may try stopping the drug. This may make the cancer shrink for a while. Doctors call this a withdrawal response.

## Androgen receptor pathway inhibitors (ARPIs)

Androgen receptor pathway inhibitors are given in addition to continuous hormonal therapy (ADT). You take them as tablets. You can take them when you first start ADT or after some time if ADT alone is no longer working for you. You usually take ARPIs for as long as they are working for you and any side effects can be managed.

ARPIs include:

- abiraterone
- enzalutamide (Xtandi®)
- apalutamide (Erleada®)
- darolutamide (NUBEQA®).

Your cancer team can give you more information about these drugs if they are suitable for you.

We have more detailed information about all these treatments on our website. Visit macmillan.org.uk/treatments-and-drugs

## Abiraterone

You take abiraterone once a day. Side effects include:

- high blood pressure
- build-up of fluid (oedema)
- tiredness (fatigue)
- low level of potassium in the blood
- changes in liver blood tests.

To reduce the risk of side effects, abiraterone is given with a daily dose of a steroid drug called prednisolone. Prednisolone can cause tummy pain or indigestion so you may also get a tablet to help prevent that.

You need to take abiraterone without food. You should not eat for 2 hours before taking abiraterone and for 1 hour afterwards.

You usually take prednisolone with or after food. This means you do not take abiraterone and prednisolone at the same time. It is important to take abiraterone and prednisolone exactly as explained. This is so they work as well as possible for you.

## Enzalutamide, apalutamide and darolutamide

If you take 1 of these drugs, you do not need to take prednisolone. You take them daily as tablets.

Side effects include:

- tiredness (fatigue)
- high blood pressure
- risk of falls and fractures.

Less commonly they can affect your memory and concentration. This is called brain fog. Darolutamide is less likely to affect the brain, but it can still happen.

Enzalutamide can affect the liver. This will be checked with regular blood tests. Rarely, it can affect the brain and cause seizures.

Apalutamide can cause a rash. It can also cause an underactive thyroid. This is called hypothyroidism. Symptoms of hypothyroidism include:

- feeling tired
- feeling cold
- gaining weight
- constipation
- low mood.

During apalutamide treatment, you will have regular blood tests to check your thyroid.

## Steroids

Sometimes a steroid drug, such as dexamethasone, is used to treat advanced prostate cancer. You usually have it when ADT is no longer working for you.

Testosterone is mainly made by the testicles. A small amount is made by the adrenal glands, above each kidney. Steroids work on the adrenal glands, reducing the amount of testosterone the body produces naturally.

You may have dexamethasone in addition to hormonal therapy (ADT). Side effects of steroids include:

- increased appetite
- weight gain
- difficulty sleeping
- irritability
- thin, fragile skin that bruises easily or takes longer to heal
- bone thinning (osteoporosis).

## Oestrogen

Less commonly, treatment with the hormone oestrogen can help to reduce the amount of testosterone the body produces naturally. It may sometimes be used when other types of hormonal therapy are no longer working.

Oestrogen can cause side effects similar to other hormonal therapy drugs for prostate cancer. Oestrogen can also increase the risk of getting a blood clot, so it may not be suitable for some people. To help prevent blood clots, your doctor may prescribe a low dose of aspirin, if suitable for you.

# Side effects of hormonal therapy

Different hormonal therapy drugs have different side effects. It is important to get information about the drugs you are having so you know what to expect.

All hormonal therapy drugs affect how the body makes and uses testosterone. The following side effects are common to most hormonal therapy drugs used for prostate cancer.

## Erection difficulties

Most hormonal therapy drugs cause loss of sexual desire (libido) and erection difficulties. This is called erectile dysfunction or ED.

Androgen deprivation therapy (ADT) usually completely stops erections during treatment. Anti-androgens stop erections in most people. If you have ED, there are drugs and treatments that may help. Your doctor or nurse will talk to you about this.

# Hot flushes and sweats

Hot flushes are a common side effect. During a flush, your neck and face may feel warm. If you have white skin, your skin may look red. If you have black or brown skin, your skin colour may deepen. Flushes can last up to 5 minutes. You might also have sweats or feel anxious or irritable during a flush. If you are having hot flushes, the following might help:

- Wear natural fabrics, such as cotton.
- Wear layers so you can remove clothes as needed.
- Use cotton sheets and layers of bedding you can remove.
- Try lying on a towel at night if you are sweating a lot.
- Try cooling pads or pillows to keep you cool.
- Keep rooms cool or use a fan.
- Have cold drinks, and avoid caffeine and alcohol.
- Try complementary therapies, such as controlled breathing or yoga.

You might have fewer hot flushes as your body adjusts to treatment. If hot flushes do not improve, talk to your cancer doctor, specialist nurse or pharmacist. Certain drugs can help to improve hot flushes. Physical activity can also help.

Anxiety can make hot flushes feel worse. Relaxation techniques might help when you can feel a flush starting.

# Tiredness (fatigue)

Feeling tired is a common side effect. It can be made worse by hot flushes affecting your sleep. Try to pace yourself and plan your day so you have time to rest between activities.

Being physically active can help to manage tiredness and give you more energy. It can also help with treatment side effects. Your cancer team can advise you about what physical activity might be suitable. Being active also:

- helps you sleep better
- reduces stress
- improves your muscle strength and bone health
- helps to maintain a healthy weight.

If tiredness if making you feel sleepy, do not drive or operate machinery.

We have more information in our booklet Coping with fatigue (tiredness) and on our website. Visit macmillan.org.uk/tired

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

## Breast swelling or tenderness

Over a longer period of time, anti-androgen treatment such as bicalutamide may cause swelling and tenderness of the breast tissue. This is called gynaecomastia. To prevent this, you may have 1 or more low doses of radiotherapy to the chest before treatment starts. You may have another type of hormonal drug to treat the breast swelling. Your cancer doctor or specialist nurse can give you more advice.

## Weight gain and loss of muscle strength

You may gain weight with hormonal therapy. This is usually around the tummy. Try to eat a healthy, balanced diet. Regular physical activity such as short walks and exercises can help keep your weight stable. It also helps to look after your muscles. Ask your cancer team for advice about how much and how often you should exercise and what activities are suitable for you.

We have more information about diet and exercise in our booklets Healthy eating and cancer and Physical activity and cancer.

# Bone thinning (osteoporosis)

Hormonal therapy can cause bone thinning. This is called osteoporosis. It can sometimes lead to tiny cracks in the bone (fractures). The risk increases if you are taking hormonal therapy for long periods of time. If you are starting long term hormonal treatment, your doctors may arrange for you to have a DEXA scan. This is a dual-energy x-ray absorptiometry scan. The scan allows your doctors to check your bones for any areas of weakness.

To help prevent or reduce bone thinning, you may be given calcium and vitamin D tablets. Your doctor may also prescribe bone-strengthening drugs called bisphosphonates. For example, you may have a drip (infusion) of zoledronic acid once or twice a year, or a weekly tablet called alendronic acid.

Weight-bearing exercises, such as walking, Pilates and yoga, can help look after your bone health. Eating a healthy balanced diet can also help.

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

# Mood changes

You may feel low or depressed, or have mood swings. This can be a side effect of hormonal therapy, but it can also be because you are coping with advanced cancer. Talking to family and friends about how you feel might help. If mood changes last for more than a few weeks, tell your doctor, nurse or pharmacist. They can talk to you about different ways to manage low mood or depression. They can also support you or refer you to get help with your emotions.

You may also find our booklets How are you feeling? The emotional effects of cancer and Coping with advanced cancer helpful.

# Chemotherapy

# Chemotherapy for advanced (metastatic) prostate cancer

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. The aim of chemotherapy for advanced (metastatic) prostate cancer is to shrink the cancer and slow its growth. This can help control the cancer, relieve symptoms and improve quality of life.

## When chemotherapy is used

Chemotherapy can be given with hormonal therapy when you are first diagnosed with advanced prostate cancer. You will start chemotherapy within 12 weeks of starting hormonal therapy with androgen deprivation therapy (ADT) or an androgen receptor pathway inhibitor (ARPI) .

When you are first diagnosed with advanced prostate cancer, you have a chemotherapy drug called docetaxel. You usually have this up to 6 times. It is usually given once every 3 weeks with a rest period in between. Each 3-week period is called a treatment cycle. You continue to have ADT and ARPI therapy.

Chemotherapy can also be given with ADT when hormonal therapy alone is no longer working for you. You may have docetaxel. The other chemotherapy drug that can be given is called cabazitaxel.

# Having chemotherapy

Chemotherapy drugs are given into a vein (intravenously). The drugs get into the blood and can reach anywhere in the body. Your cancer team can talk to you about your treatment plan.

You can have chemotherapy drugs through:

- a cannula – a short, thin tube the nurse puts into a vein in the arm or hand
- a central line – a fine tube that goes under the skin of the chest and into a vein close by
- a PICC line – a fine tube that is put into a vein in the arm and goes up into a vein in the chest.

Having chemotherapy

# Side effects of chemotherapy

The side effects you get will depend on which chemotherapy drug you are having. You may get some of the side effects we mention here, but you are unlikely to get all of them. You may get other side effects we do not mention. We have more information about the side effects of the individual drugs on our website. Visit macmillan.org.uk/treatments-and-drugs

Some side effects are mild and can be treated easily. Your cancer team or pharmacist may give you drugs to help control them.

Many side effects stop or gradually get better after chemotherapy has ended.

Very common side effects of chemotherapy for advanced (metastatic) prostate cancer include the following.

## Risk of infection

Chemotherapy can reduce the number of white blood cells in your blood. These cells fight infection. If your white blood cell count is low, you may be more likely to get an infection. A low white blood cell count is called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. If you have any of the following symptoms, contact the hospital straight away on the 24-hour number:

- a temperature above 37.5°C
- a temperature below 36°C
- you feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- diarrhoea
- needing to pass urine (pee) often, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

Your white blood cell count will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

Some people may be given a drug called G-CSF. This encourages the body to make more white blood cells. You have it as a small injection under the skin. We have more information about this on our website at macmillan.org.uk/g-csf

# Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- tiny red, brown or purple spots that may look like a rash – these spots can be harder to see if you have black or brown skin.

If you have any unexplained bruising or bleeding, contact the hospital straight away on the 24-hour number. You may need a drip to give you extra platelets. This is called a platelet transfusion.

# Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may feel:

- very low in energy
- breathless
- dizzy and light-headed.

If you have these symptoms, contact the hospital straight away on the 24-hour number. You may need treatment for anaemia. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

## Feeling sick

Your doctor, nurse or pharmacist will prescribe anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as they tell you to, even if you do not feel sick. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluid often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or if you are sick (vomit) 1 to 2 times in 24 hours, contact the hospital on the 24-hour number as soon as possible. They will give you advice. They may change your anti-sickness treatment. Let them know if you still feel sick.

## Loss of appetite

Chemotherapy can affect your appetite. Don't worry if you do not eat much for 1 or 2 days. But if your appetite does not come back after a few days, or if you are losing weight, tell your doctor, nurse or pharmacist. They can give you advice. They may give you food or drink supplements. Or they may suggest changes to your diet or eating habits to help.

# Sore mouth and throat

Chemotherapy may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

Contact the hospital straight away on the 24-hour number, if:

- a sore mouth or throat affects how much you can drink or eat
- your mouth, tongue, throat or lips have any blisters, ulcers or white patches.

They can give you advice, and mouthwash or medicines to help with the pain or to treat any infection. Follow their advice and make sure you:

- drink plenty of fluids
- avoid alcohol and tobacco
- avoid food or drinks that irritate your mouth and throat.

# Hair loss

Your hair will get thinner. Or you may lose all the hair from your head. You may also lose your eyelashes and eyebrows, as well as other body hair. Hair loss usually starts after your first or second treatment.

Scalp cooling is a way of lowering the temperature of your scalp to help reduce hair loss. Your nurse can tell you whether this is an option for you.

If you want to cover up hair loss, there are different ways you can do this. Your nurse will give you information about coping with hair loss.

Remember to protect your skin from the sun. Use suncream with a sun protection factor (SPF) of at least 30 on your scalp. Or cover up with a hat or scarf.

Hair loss is almost always temporary. Your hair will usually grow back after treatment ends.

# Feeling tired

Feeling tired is a common side effect of chemotherapy. It is often worse towards the end of treatment and for some weeks after it ends. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can help you feel less tired.

If you feel sleepy, do not drive or use machinery.

## Diarrhoea

Chemotherapy may cause diarrhoea. Diarrhoea means passing more stools (poo) than is normal for you, or having watery or loose stools. You may also have stomach cramps. If you have a stoma, it may be more active than usual.

If you are passing loose stools 3 or more times a day and this is not normal for you, contact the hospital as soon as possible on the 24-hour number. Follow the advice they give you about:

- taking anti-diarrhoea medicines
- drinking enough fluids to keep you hydrated and to replace lost salts and minerals
- any changes to your diet that might help.

They might also ask you for a specimen of your stool to check for infection.

## Numb or tingling hands or feet (peripheral neuropathy)

Chemotherapy may affect the nerves in your fingers and toes. This can cause numbness, tingling or pain in your hands or feet. This is called peripheral neuropathy. You might find it hard to do fiddly tasks such as fastening buttons or tying shoelaces.

If you have these symptoms, always tell your doctor, nurse or pharmacist. They sometimes need to change the drug or the dose of the drug. The symptoms usually improve slowly after treatment ends. But for some people they continue and are a long-term side effect of treatment.

> **"The first 6 rounds of treatment I experienced no side effects whatsoever, but the next 2 knocked me sideways and I had diarrhoea and tiredness. Other than that, I felt fine. „**

Colin, diagnosed with prostate cancer


our Vision is

# Radioisotope therapy

# Radioisotope therapy for advanced (metastatic) prostate cancer

Radioisotope therapy can be used to treat prostate cancer that has spread to the bones and is causing pain. It is not suitable for prostate cancer that has spread to other areas. You may have a radioisotope if hormonal therapy (ADT) is no longer helping to control prostate cancer in the bones. It may be given after chemotherapy treatment.

This treatment uses a radioactive substance called a radioisotope which is injected into a vein. Radioisotopes are more easily absorbed by cancer cells than normal cells. This means cancer cells get a higher dose of radiation while normal cells are protected. All areas of bone affected by cancer will be treated. Radioisotope therapy can be helpful when cancer affects many areas of bone.

The radioisotope used is called radium-223 (Xofigo®). You usually have it once every 4 weeks, for 6 treatments. You have radioisotope treatment as an outpatient in the nuclear medicine department of a hospital. You go home on the same day.

Before radioisotope therapy, you have a blood test to make sure your blood cells are at a normal level. This is because radioisotopes can reduce the number of blood cells.

The radiographer gives you the radioisotope as an injection into a vein in the arm. This only takes a few minutes. When they are finished, they cover the area with a small plaster.

After the injection, you will have some radioisotopes in your stools (poo), urine (pee) and blood. This means you need to do things to protect yourself and others from radiation when you go to the toilet. You only need to take precautions for 1 week. Your cancer team will advise you to sit down to use the toilet rather than standing or using a urinal. You will be asked to flush the toilet twice with the lid down. You will also need to wear gloves if you need to clean up bodily fluids.

It is usually still safe for you to be in contact with other people, including children. But close contact may not be recommended for a few days after treatment. Your cancer team will explain more about protecting others from radiation. They will advise you about any extra precautions you need to take.

Your cancer team can also talk to you about having sex while having this treatment. They will advise you about any precautions to take to protect you or a partner. It is also important not to make someone pregnant after radioisotope therapy and for at least 6 months after treatment finishes. Your cancer team will advise you about what types of contraception to use and for how long.

## Side effects of radioisotope therapy

The side effects of radioisotope therapy are usually mild. You may have some diarrhoea or feel slightly sick. Your doctor can give you drugs to control these effects if needed. It can also make you feel tired for a while. Sometimes it can cause a flare (worsening) in symptoms such as pain, but this usually improves quite quickly.

The treatment can sometimes reduce the number of blood cells for a short time. This is usually not a problem. But if you notice any unusual bruising or bleeding, contact the hospital straight away on the 24-hour number you have been given.

# Radiotherapy

# Radiotherapy for advanced (metastatic) prostate cancer

Radiotherapy uses high-energy rays to treat cancer. It destroys cancer cells in the area where it is given. It can be given in different situations to treat advanced (metastatic) prostate cancer.

You have external beam radiotherapy for advanced prostate cancer. This means it is given from a machine outside the body (externally).

If you are having radiotherapy, you will see a clinical oncologist and a specialist therapeutic radiographer. A clinical oncologist is a cancer doctor who specialises in radiotherapy, chemotherapy and other drugs to treat cancer. Therapeutic radiographers are experts in radiotherapy and are specially trained in cancer treatment. They can also give you support, advice and information about your radiotherapy.

# Radiotherapy to the prostate gland

If you have been newly diagnosed with advanced prostate cancer, your cancer team might talk to you about radiotherapy to the prostate gland. Research has shown that treating the prostate can help with symptoms, even when the cancer has spread to other areas. It can also help some people live longer. But radiotherapy to the prostate is not suitable for everyone.

You usually have radiotherapy once a day, Monday to Friday, over 4 weeks. Sometimes you have it once a week for 5 to 6 weeks.

Having radiotherapy

# Palliative radiotherapy

When radiotherapy is used to relieve symptoms, it is called palliative radiotherapy.

Radiotherapy for advanced prostate cancer is most often used to shrink cancer that has spread to the bones.

It can strengthen the bone and reduce pain. This helps to keep you as active as possible. Sometimes treatment to the bones may also help to control the cancer.

Your pain may get better within a few days of having radiotherapy. Or it may take a few weeks. It may be up to 6 weeks before you feel the full benefit. Often, the pain gets worse before it gets better, especially in the first few days after treatment.

You will need to keep taking painkillers during this time. Tell your cancer doctor, therapeutic radiographer or nurse if the pain gets worse so they can adjust your painkillers until your symptoms improve.

Radiotherapy can also help to treat:

- pain from the cancer in the prostate
- pain if the cancer is in a lymph node or pressing on the bowel (rectum)
- blood in the urine (pee).

## Radiotherapy for metastatic spinal cord compression (MSCC)

Sometimes cancer in the bones of the spine grows and presses on the spinal cord. This may stop the spinal cord nerves from working properly. This is called metastatic spinal cord compression or MSCC.

MSCC can be treated with external beam radiotherapy to the spine. You usually have a single treatment. Some people may have surgery or cancer drugs to treat MSCC. You may also be given steroids to relieve the compression.

Get more details about MSCC. We also have more information on our website and in our leaflet about MSCC.

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

# Planning external beam radiotherapy

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

You will have a hospital appointment to plan your treatment. During the planning visit, you will have a CT scan. The scan is to help your radiotherapy team decide on the dose and the area to treat. 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 radiotherapy is called a therapeutic radiographer. They may make some permanent marks (tattoos) the size of a pinpoint on your skin. These are used to make sure you are in the correct position for your treatment. They also show where the radiotherapy machine will direct its rays. The marks are only made with your permission. It may be a little uncomfortable. If you are worried about this, talk to the radiographer.

# If you are having radiotherapy to the prostate

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

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

You may be advised to start pelvic floor exercises. Doing these exercises before, during and after your radiotherapy can help with bladder side effects.

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

# Having external beam radiotherapy

You usually have external beam radiotherapy in a hospital radiotherapy department as an outpatient. The radiotherapy machine looks like a big x-ray machine. It is called a linear accelerator or LINAC.

You may have external beam radiotherapy as a single treatment or as a series of short, daily or weekly treatments called fractions. If you are having multiple treatments, they are given from Monday to Friday, with a break at the weekend.

At the start of a treatment session, the therapeutic radiographer will make sure you are in the correct position on the couch and that you are comfortable. Radiotherapy is not painful. But you must lie still during the treatment. If you are planning to take painkillers, you may want to take them before you have treatment.

When everything is ready, the therapeutic radiographer leaves the room so you can have the radiotherapy. The treatment only takes a few minutes. You can talk to them through an intercom or signal to them during the treatment. They can see and hear you from the next room.

Your clinical oncologist, specialist nurse or therapeutic radiographer will explain your treatment and its possible side effects. They can give you advice on what you can do to manage any side effects. They can also help answer any questions you may have.

# Side effects of radiotherapy to the prostate

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

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

Always tell them about your side effects rather than trying to treat them yourself. There are usually things they can do to help.

We have more detailed information about the effects of radiotherapy to the prostate in our booklet Understanding pelvic radiotherapy and on our website. Visit macmillan.org.uk/pelvic-radiotherapy

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

# Bowel side effects during treatment

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

If you have diarrhoea, drink at least 2 to 3 litres (8 to 12 glasses) of fluids a day. Avoid caffeine and alcohol. During treatment, your radiographer may advise you to make some changes to your diet, such as eating less fibre.

Bowel side effects usually improve by 6 weeks after finishing treatment.

# Bladder side effects during treatment

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

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

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

If you are having problems, you may need to have a tube put into the bladder to drain urine. This is called a urinary catheter. Or you may be prescribed tablets to help you pass urine.

Side effects can be worse if you already had bladder problems before starting radiotherapy. But you may still find these problems start to improve after radiotherapy finishes.

## Late bladder effects

Frequency and urgency may not completely go away, or they may develop later. Sometimes radiotherapy can affect how well your bladder can hold urine.

The bladder lining may bleed easily, causing blood in your urine (haematuria). You may get leakage of small amounts of urine. This is called urinary incontinence. But it is rare. We have more information about how bladder problems may be treated on our website.

## Tiredness

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

- getting plenty of rest, but keeping your daily routine if you feel able to
- doing some regular exercise, such as going for a walk
- eating a healthy diet and drinking plenty of fluids
- asking for help with everyday tasks.

After treatment finishes, tiredness should improve. If it does not get better after a few weeks, tell your cancer team. We have more information in our booklet Coping with fatigue (tiredness) and on our website.

# Effects on the skin

Less commonly, radiotherapy may affect the skin in the treated area. White skin may become red. Black or brown skin may look darker.

Skin may also become dry or flaky, and feel itchy or tight. Sometimes the skin around the anus and scrotum becomes moist and sore. Your therapeutic radiographer will give you advice. Your cancer team can prescribe a cream or dressings and painkillers if you need them. Do not apply anything to the area without checking with your radiographer first.

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).

Having hormonal therapy also causes loss of sexual desire and erection difficulties. Erections usually stop completely during androgen deprivation therapy (ADT).

# Side effects of palliative radiotherapy

The side effects of palliative radiotherapy are usually mild. They will depend on the area being treated. Always tell your cancer team about any side effects. There are usually ways to treat or manage them.

## Tiredness

Feeling very tired is a common side effect. This should gradually improve a few weeks after treatment finishes. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

We have more information in our booklet Coping with fatigue (tiredness).

## Feeling sick

You may feel sick if the area treated is close to your tummy – for example, the ribs or spine. Your doctor can give you anti-sickness drugs to help prevent or control sickness. If you only have 1 or 2 treatment sessions, you may have flu-like symptoms for a few days afterwards.

# Surgery

# Surgery for advanced (metastatic) prostate cancer

Surgery can be used to help control advanced (metastatic) prostate cancer and relieve symptoms. Surgery can be used:

- instead of hormonal therapy, to reduce testosterone
- if the cancer is making it difficult to pass urine (pee)
- to strengthen a bone.

Surgery to remove the prostate gland (radical prostatectomy) is not used to treat advanced prostate cancer. This is because a radical prostatectomy cannot cure prostate cancer once the cancer cells have spread outside the prostate gland and nearby area.

## Surgery to reduce testosterone

Some people may have surgery, instead of hormonal therapy, to reduce the amount of testosterone the body produces naturally. The operation involves removing part of the testicles. This is called a subcapsular orchidectomy. This surgery is not reversible, so the hormonal effects are permanent. It is rarely done now, as most people have hormonal therapy to reduce testosterone instead.

Your cancer team may talk to you about this surgery if you are not keen to have hormonal therapy drugs. You usually just go into hospital for the day. Your cancer team can tell you more about the operation and any side effects.

## Surgery for problems with passing urine

Surgery can be used to help if the cancer is affecting the flow of urine through your:

- ureters – the tubes that drain urine from the kidneys into the bladder
- urethra – the tube that you pass urine out of the body from.

Surgery for prostate cancer that is affecting the urethra is called a transurethral resection of the prostate (TURP). Surgery for prostate cancer that is affecting the ureters will either be a percutaneous nephrostomy or JJ stent.

## Surgery to strengthen a weakened bone

Prostate cancer that has spread to the bones may cause problems that need treating with surgery. If you are at risk of a broken bone, your doctor may advise surgery to repair or strengthen the bone to help prevent it from breaking in the future.

# Going home after surgery

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

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

Your surgeon or specialist nurse can give you advice on when you can start doing things such as driving or returning to work.

# Transurethral resection of the prostate (TURP)

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

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

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

## Having a TURP

Before surgery, you may have a pre-operative assessment. This may involve having some tests to check your general health and fitness.

A TURP can be done under a general anaesthetic (where you are asleep). Or you may have a spinal anaesthetic, where you have an injection of anaesthetic around your spine.

We have more information about pre-operative assessements and types of anaesthetic at macmillan.org.uk/going-into-hospital

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

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

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

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

# After your TURP

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

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

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

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

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

## Urinary catheter

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

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

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

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

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

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

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

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

### Preventing blood clots

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

## Side effects of a TURP

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

### Pain

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

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

## Ejaculating into the bladder

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

## Erection problems

Having a TURP can cause problems getting or keeping an erection. This is called erectile dysfunction (ED).

Having hormonal therapy also causes loss of sexual desire and erection difficulties. Erections usually stop completely during androgen deprivation therapy (ADT) .

## Difficulty passing urine

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

# Percutaneous nephrostomy or JJ stent

The tubes that drain urine from the kidneys to the bladder (ureters) may get blocked by prostate cancer. This will make it difficult to pass urine (pee). If this happens, you may be offered 1 of the following types of surgery:

- Percutaneous nephrostomy – the doctor, guided by a scan, puts a tube into the kidney. The tube goes into a bag that sits outside on the skin. Urine can then drain into the bag.
- JJ stent, also called a ureteric stent – this is when the doctor puts a fine tube into the ureter. This opens up the ureter so urine can flow through it.

A planned percutaneous nephrostomy can often be done under a local anaesthetic with a sedative (a drug to make you relaxed and sleepy). You usually do not need to stay in the hospital overnight.

Your cancer team can give you more information about both these types of surgery. We also have information about them on our website:

- macmillan.org.uk/nephrostomy
- macmillan.org.uk/ureteric-stent

# Coping with cancer

# Coping with advanced (metastatic) cancer

It is common to have many different reactions and feelings when you find out that you have advanced (metastatic) cancer or that cancer has come back or spread. You may feel shocked and find it hard to understand. You may feel angry or frightened about the future.

These feelings can be difficult. They usually become easier to manage over time and as you start making decisions and plans. We have information about coping with difficult feelings in our booklet How are you feeling? The emotional effects of cancer.

You may also find our booklet Coping with advanced cancer helpful.

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

# Managing symptoms

Advanced (metastatic) prostate cancer can cause physical symptoms that are difficult to cope with. But there are ways to manage or control them. For example, if you are having hormonal therapy or chemotherapy to control the cancer, this may help improve any symptoms you have.

Your cancer team can support you. You may see healthcare professionals who specialise in pain and symptom control. They are called the palliative care team.

Other healthcare professionals can also help. A physiotherapist can advise you if you have problems with mobility. They can plan an exercise programme and help you build your muscle strength. Occupational therapists can help with equipment that makes it easier and safer to manage at home.

Our booklets Managing cancer pain and Managing the symptoms of cancer may help.

# Tiredness

You may feel extremely tired (fatigued). This can be because of the cancer and treatment side effects. There are things you can do to help manage tiredness:

- Pace your everyday activities and save energy for things you want or need to do.
- Accept offers of help from others, or ask for help when you need it.
- Try to be more physically active to improve your energy levels – for example, by going for regular short walks or doing yoga or Pilates. We have more information in our booklet Physical activity and cancer.
- Eat healthily to give you more energy and help you feel better. Prepare meals when you are feeling less tired, to eat when you do not want to cook. Our booklet Healthy eating and cancer has more information.
- Try some complementary therapies such as relaxation techniques, which may help you to feel less anxious and tired. Our booklet Cancer and complementary therapies has more information.

If you are having problems with your mobility or daily tasks, ask to see a physiotherapist or occupational therapist. Using a walking aid may allow you to move more easily.

Tell your doctor or nurse if you are very tired. They can test your blood for anaemia (a low level of red blood cells). Anaemia can make you feel tired, dizzy and short of breath. Sometimes a blood transfusion is needed to treat anaemia.

# Pain

Always tell your cancer team if you have pain. Different painkillers work in different ways. You can take painkillers:

- by mouth
- as injections under the skin
- as patches on the skin.

If pain is an ongoing problem, you may be advised to take painkillers regularly rather than as you need them. Even if you are not in pain when the next dose is due, taking regular painkillers can stop pain coming back. If your painkillers are not working well, tell your cancer team. They can adjust the dose or give you a different type.

Many hospitals have specialist pain teams. The team includes doctors, nurses and usually an anaesthetist. Some teams also have a psychologist. Your cancer team can refer you to a pain clinic if that might be helpful.

We have more information in our booklet Managing cancer pain.

## Treating bone pain

A common place for prostate cancer to spread to is the bones. This is called secondary cancer in the bone. There are different ways bone pain can be controlled. You may have:

- drugs called non-steroidal anti-inflammatory drugs (NSAIDs)
- a bone-strengthening drug called a bisphosphonate
- 1 or 2 sessions of radiotherapy.

Radiotherapy can help with bone pain but it can take a few weeks to feel the effect. Follow any advice about taking your painkillers regularly until the radiotherapy works.

## Bisphosphonates

If your cancer has spread to the bones, you may have a bisphosphonate called zoledronic acid as a drip (infusion) into a vein. You have this in the outpatient department every 3 to 4 weeks.

This can help to:

- strengthen bone
- lower the risk of bone fracture
- reduce bone pain.

Bisphosphonates can help prevent or reduce bone thinning (osteoporosis). This can be a side effect of long term hormonal therapy. In this situation, you may have zoledronic acid once or twice a year or a weekly tablet called alendronic acid. You also have calcium and vitamin D tablets with bisphosphonate treatments.

We have more information about bisphosphonate treatments on our website. Visit macmillan.org.uk/bisphosphonates

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

# Bone problems

For some people, secondary cancer in the bone may cause other problems that need treatment. There are ways of managing these problems.

## Strengthening a weakened bone

If there is a risk of a bone breaking, your doctor may advise surgery to strengthen or repair the bone. An orthopaedic surgeon does this surgery. You have it under a general anaesthetic (while you are asleep).

The surgeon puts a metal rod down the middle of the bone or fixes a metal plate onto the outside of the bone. This holds the bone so that it will not break. The rods or plates stay in permanently. They are mainly used to treat the long bones in the legs.

Depending on where the cancer is in the bones, you may have surgery to strengthen the spine or replace a hip joint.

How long you stay in hospital can depend on your situation and the surgery you have had. We have more information about recovering from surgery on our website. Visit macmillan.org.uk/surgery

You may have radiotherapy before or after surgery. This can help repair the bone or destroy any cancer cells.

> “The cancer had spread and weakened the bone. The first challenge was to get a steel rod put into my right femur bone.„
>
> John, diagnosed with prostate cancer

## Metastatic spinal cord compression (MSCC)

Sometimes cancer in the bones of the spine grows and presses on the spinal cord. This may stop the spinal cord nerves from working properly. This is called metastatic spinal cord compression or MSCC.

MSCC is not common, but it needs to be treated quickly. This is to stop permanent damage to the nerves.

MSCC can be treated with radiotherapy to the spine. You usually have a single treatment. Some people have surgery or cancer drugs to treat MSCC. You may also be given steroids to relieve the compression.

MSCC causes symptoms such as:

- a new pain in your neck or back
- numbness or pins and needles in your feet or hands
- weakness in your arms and hands
- difficulty walking or weakness in your legs
- bladder problems such as leaking urine (incontinence) or passing little or no urine (pee)
- bowel problems such as incontinence or new or worsening constipation.

**If you develop any of these symptoms, you should get medical advice immediately. Contact someone straight away, even if it is the weekend or a holiday.**

You should contact the hospital team where you usually go for cancer treatment and follow-up appointments. Make sure you have their contact details and that you know who to call in the evenings and at weekends. If you are unable to contact anyone, go to the nearest A&E (emergency department) straight away.

You can read more about MSCC on our website at macmillan.org.uk/malignant-spinal-cord-compression and download our **MSCC alert card** from orders.macmillan.org.uk

## Hypercalcaemia

If cancer has spread to the bones, it can cause calcium to be released into the blood. This is called hypercalcaemia. It is not common with prostate cancer.

High levels of calcium in the blood can make you feel:

- sick (nausea)
- thirsty
- drowsy
- confused and unwell
- constipated
- that you are passing urine (peeing) more often.

**If you develop any of these symptoms, it is very important to let your doctor or specialist nurse know straight away.**

You may need to spend a few days in hospital having treatment to reduce your calcium levels. Your doctor or nurse may ask you to drink a lot. They will probably also give you fluids into a vein in the arm (intravenous infusion). This helps your body to get rid of the calcium.

Your doctor may give you a dose of bisphosphonate through a drip (infusion).

You can have treatment more than once if the calcium levels rise again. You should feel much better within a couple of days.

# Bladder or bowel problems

Advanced prostate cancer can cause bladder or bowel problems, such as needing to go to the toilet frequently or urgently, or leakage (incontinence). There is help available. Your cancer team can advise you, or put you in touch with a continence service. There are different products and pads you can use and treatments that can help. The Bladder and Bowel Community and Continence Product Advisor websites have useful information.

Some people may need a urinary catheter to help with bladder problems. A catheter is a small, flexible plastic tube put into the bladder. It drains urine into a bag. Some people need a catheter while they recover from treatment. Other people may need a catheter for a longer period, to manage ongoing symptoms.

If you have radiotherapy to the prostate gland or nearby areas (pelvic radiotherapy), you may develop bladder and bowel problems later. There are different ways to manage the late effects of pelvic radiotherapy. We have more information in our booklets Managing the bladder late effects of pelvic radiotherapy and Managing the bowel late effects of pelvic radiotherapy.

If you have diarrhoea, your doctor can give you drugs to help.

You may also have constipation. Constipation can be caused by:

- some types of painkiller
- being less active than usual
- not eating enough high-fibre foods.

Things that help with constipation include:

- having more fibre in your diet
- drinking plenty of fluids
- going for regular short walks.

Your doctor may need to give you a medicine called a laxative to make your bowels work. If you take regular strong painkillers, you may be given a laxative to help prevent constipation.

## Macmillan toilet card

We have a card you can order if you are having bowel or bladder problems. If you need to use a toilet urgently, you can show this card in places such as shops, offices, cafes 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.

If you have problems with bladder or bowel control, you may feel worried about going out, especially to somewhere new. Planning ahead so that you are prepared can help you feel more confident.

We have more information about tips for going out and access to toilets. Visit macmillan.org.uk/bladder-bowel-problems

## Blockage in the kidney or ureter

The tubes that connect the kidneys to the bladder (ureters) may get blocked by prostate cancer. This will make it difficult to pass urine. If this happens, you may be offered surgery.

Your doctor or specialist nurse can give you more information about these types of surgery.

## Eating problems

If you have eating problems or are worried about losing weight or gaining weight, there is lots of information to help you. You can ask your nurse or a dietitian for advice.

If you have lost weight, food supplements can provide more protein and energy, and help improve your weight. A dietitian can give you advice on this. If your appetite is not good, try eating small meals often and sipping nutritional drinks. You can get some of these on prescription.

Weight gain can be a side effect of hormonal therapy. Healthy eating and cutting down on foods that are high in fat or sugar can help manage your weight. Try to only eat as much as you need. Try to combine this with physical activity, such as regular short walks.

Our website has more information at macmillan.org.uk/eating-problems

# Looking after your wellbeing

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

## Healthy eating

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

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

## Keeping active

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

## Stop smoking

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

We have more information at macmillan.org.uk/stop-smoking

## Look after your bones

Hormonal therapy for prostate cancer can increase the risk of bone thinning. This is called 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. Smoking can also increase your risk of bone thinning.

## Limit alcohol

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

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

# Complementary therapies

You may find that complementary therapies, such as relaxation techniques, massage or aromatherapy, can help you to relax your mind and body, improve your mood and relieve tension. They may reduce symptoms of anxiety or help with pain. Tell your cancer team if you plan to use any complementary therapies. They can advise you whether a complementary therapy is suitable for your situation. It is also important to use a qualified therapist and tell them about your cancer diagnosis.

We have the following booklets about health and wellbeing:

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

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

# Sexual wellbeing

Prostate cancer and its treatments will usually affect your sexual wellbeing in some way. It is not always easy to talk about this. But it is important to have your questions answered and to get the help you need. You do not have to be in a relationship or having sex to have questions or need support.

Your GP, cancer doctor or specialist nurse can advise and support you. They can refer you to specialist services if that might help.

Whoever you talk to 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. Plan what you want to say in advance and write down your questions. You do not need to use medical words. Use the words you normally use. This can help the professionals understand how to best support you.

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.

There is also other support available. You can talk to in confidence to a cancer information nurse specialist on the Macmillan Support Line or through email. Prostate Cancer UK also has a helpline and options to chat online to a specialist prostate nurse.

We also have the following booklets about sexual wellbeing and relationships:

- Cancer and your sex life
- Cancer and relationships – support for partners, families and friends
- Talking about cancer.

# If you are LGBTQ+

Your healthcare team are there to support you and treat you in a way you feel comfortable with. There may be times when it helps them to know your gender identity or sexual or romantic orientation. This may help you feel better supported. And it also helps your healthcare team give the right information and support to you and your partner if you have one.

The side effects of cancer treatment are often the same whatever your sexual orientation or gender identity. But as an LGBTQ+ person, you may have some specific questions about how side effects will affect your sexual wellbeing. And some side effects may be more of a problem depending on the type of sex you have.

Our prostate cancer information is for everyone affected by prostate cancer. You may also find the following resources helpful:

- Prostate Cancer UK has more information for gay and bisexual men and trans (transgender) women
- LGBT Foundation can give you confidential advice and support
- OUTpatients can offer support services and information.

We also have more information at macmillan.org.uk/lgbtq

# Managing sexual difficulties

Cancer and cancer treatment can affect many areas of sexual wellbeing. There are different ways of managing any changes and improving your sexual wellbeing. Ask your cancer team or GP for advice or treatments that can help. They may refer you to someone else if you need more help.

Sometimes the symptoms of the cancer, or side effects of treatment, can make it difficult to have sex. For example, you may feel too tired or have discomfort that makes sex difficult.

Feelings such as anxiety or low mood can also affect how you feel about sex. They can also affect how you feel and think about your body. This is called body image. Your body image may affect how you feel about being intimate with another person. You may worry these changes will affect how attractive you are to other people. We have more information in our booklet Body image and cancer.

Prostate cancer treatments can also have a direct effect on sexual wellbeing. Your cancer team can explain the most likely effects of your treatment. These may include:

- a reduced sex drive (libido) or loss of interest in sex
- difficulties getting or keeping an erection
- difficulties having an orgasm or ejaculating
- hormonal therapy causing the penis and testicles to get smaller.

# Erection problems

Loss of sex drive (libido) and erection difficulties are common side effects during hormonal therapy. Radiotherapy and surgery for prostate cancer can also affect erections.

There are no treatments to increase sex drive if you are having hormonal therapy. But if you have problems getting or keeping an erection, you may be able to use a treatment such as:

- tablets
- injections
- pellets or creams
- pumps.

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

If these treatments do not work for you, your healthcare team may talk to you about penile implants. A penile implant is either a semi-rigid rod that can keep the penis firm all the time and can be bent down when an erection is not needed. Or it can be an inflatable rod that you inflate when you want an erection. These are not always available on the NHS.

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

We have more information about managing sexual difficulties and erection problems in our booklet Cancer and your sex life.

> "Did I feel less of a man? Yes. Still do to a degree. But the love of my wife and her emphasis on the sensual side and the need to 'make love' (not just enjoy sex sessions) are of enormous help. „

Elvin, diagnosed with prostate cancer

# Fertility

Treatments for prostate cancer can cause infertility. This means you will no longer be able to get someone pregnant naturally.

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

We have more information in our booklet Cancer and fertility and on our website at macmillan.org.uk/fertility

# Your feelings and relationships

# Your feelings

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

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

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

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

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

Get more information about other ways we can help you.

## 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.

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

> **"Friends find it difficult to talk to you. How do you deal with that? People are frightened of asking questions, in case they upset people. Talking frankly about it helps you put the issues on the table. It is much better to share things."**
>
> Tim, diagnosed with prostate cancer

# 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.

# Relationships

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

We have more information about relationships online and in our booklets Talking about cancer and Cancer and relationships: support for partners, families and friends.

## 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.

We have more information in our booklets Talking about cancer and Cancer and your sex life.

## 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.

## If you are a family member or friend

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

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

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet Looking after someone with cancer.

## Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

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

> "I was the provider
> and all of a sudden
> I became the person
> who was cared for.
> It's quite a change.
> You suddenly question
> your purpose in life. „

Tim, diagnosed with prostate cancer

# Work and financial support

# Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers. Visit macmillan.org.uk/benefits

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

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

The benefits system and other types of financial support can be hard to understand. Macmillan has expert money advisers who can talk to you about your money worries, provide information about benefits and recommend other useful organisations that can help.

You can speak to them by calling the Macmillan Support Line on 0808 808 00 00. Please note the opening times may vary by service.

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

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

## Grants

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

## Insurance

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

We have more information about travel insurance in our booklet Travel and cancer. Our Online Community forum on Travel insurance may also be helpful. Visit macmillan.org.uk/community

> "My director put me in touch with someone else in the company in a similar boat. Just talking through the issues we were both facing really helped me. I also shared my story and have since helped to support more colleagues living with cancer. „

David, diagnosed with prostate cancer

# Work

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

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

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

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

Our booklets have more information that may be helpful:

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

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

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

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

# Further information

# About our information

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

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

## Order what you need

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

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

## Online information

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

## Other formats

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

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

Find out more at macmillan.org.uk/otherformats

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

## The language we use

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

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

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

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

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

# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

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

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

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

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

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

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

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

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

## Macmillan Information and Support Centres

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

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

## Help with money worries

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

### Financial advice

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

### Help accessing benefits

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

## Help with work and cancer

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

## Talk to others

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

### Support groups

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

### Online Community

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

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

## Macmillan healthcare professionals

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

# Other useful organisations

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

## Prostate cancer support organisations

### Orchid

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

### Prostate Cancer UK

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

### Prostate Scotland

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

### Tackle Prostate Cancer

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

## Sex and relationship support

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

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

### Prostate Cancer UK sexual support service

Helpline **0800 074 8383**
https://prostatecanceruk.org/sexual-support
A service where you or your partner can talk to a specialist nurse who can help with sexual problems after treatment for prostate cancer.

## General cancer support organisations

### Bladder & Bowel Community

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

### Cancer Black Care

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

### Cancer Focus Northern Ireland

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

### Cancer Research UK

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

### Continence Product Advisor

www.continenceproductadvisor.org
A website offering advice on different types of continence product, helping people identify products and combinations to suit their needs.

### Macmillan Cancer Voices

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

### Maggie's

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

### Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

### Tenovus

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

## General health information

### Drinkaware

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

### Health and Social Care in Northern Ireland

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

### NHS.UK

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

### NHS 111 Wales

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

### NHS Inform

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

### Patient UK

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

## Stop smoking services

### NHS Smokefree Helpline (England)

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

### Quit Your Way (Scotland)

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

### Help Me Quit (Wales)

Tel **0800 085 2219**
Text **'HMQ' to 80818**
www.helpmequit.wales
Offers information, advice and support on stopping smoking in English and Welsh.

### Stop Smoking NI (Northern Ireland)

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

## Counselling

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

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK.

### UK Council for Psychotherapy (UKCP)

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

## Emotional and mental health support

### Mind

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

### Samaritans

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

## Financial support or legal advice and information

### Advice NI

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

### Citizens Advice

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

### England

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

### Scotland

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

### Wales

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

### GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

## Support for older people

### Age UK

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

## LGBT-specific support

### LGBT Foundation

Tel **0345 330 3030**
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.

### OUTpatients

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

### Out with Prostate Cancer

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

## Support for carers

### Carers Trust

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

### Carers UK

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

## Advanced cancer and end of life care

### Hospice UK

Tel **0207 520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

### Marie Curie

Helpline **0800 090 2309**
www.mariecurie.org.uk
Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

### The Natural Death Centre

Helpline **0196 271 2690**
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

## Cancer registries

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

### England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

### Scotland – Public Health Scotland (PHS)

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

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

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

### Northern Ireland – Northern Ireland Cancer Registry (NICR)

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

# Your notes and questions

# 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 Ursula McGovern, Consultant Medical Oncologist.

With thanks to: Leanne Alder, Prostate Advanced Practitioner Radiographer; Professor Alison Birtle, Consultant Clinical Oncologist; Janet Forgenie, Uro-Oncology Clinical Nurse Specialist Lead; Professor Duncan McLaren, Consultant Clinical Oncologist; Mr Werner Struss, Consultant Urological Surgeon; Dr Naveen Vasudev, Consultant Medical Oncologist; and Deborah Victor, Uro-Oncology Clinical Nurse Specialist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories. This includes Colin. Sadly, Colin died in 2024. We'd like to thank his family for allowing us to continue sharing his story so others can benefit from Macmillan's support.

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

## Sources

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

Prostate cancer: diagnosis and management. NICE guideline [NG131] Published: 09 May 2019 Last updated: 15 December 2021 https://www.nice.org.uk/guidance/ng131 [accessed October 2024].

Parker, C. et al. Prostate cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology, Volume 31, Issue 9, 1119–1134 https://www.annalsofoncology.org/article/S0923-7534(20)39898-7/fulltext#articleInformation [accessed October 2024].

# Can you do something to help?

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

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

## 5 ways you can help someone with cancer

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

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

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

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

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

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

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

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

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

## Do not let the taxman keep your money

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

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

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

MACMILLAN
CANCER SUPPORT

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

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

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

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

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

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

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