MACMILLAN CANCER SUPPORT

# UNDERSTANDING EARLY (LOCALISED) PROSTATE CANCER

‘I was diagnosed with prostate cancer when I was 37. I have since had the opportunity to use my experiences to help others and put their minds at rest as much as I could.’

Simon, diagnosed with early prostate cancer

# About this booklet

**This booklet is for anyone who has been diagnosed with early (localised) prostate cancer. This is when the cancer is only inside the prostate and has not spread outside it. There is also information for family members and friends.**

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

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

## How to use this booklet

As this booklet includes information on different treatments and side effects, not every section will apply to you. For example, the sections on treatments are split depending on which type you have. You may want to read about the different treatments to help you make decisions about your treatment.

You do not have to read the booklet from start to finish. You can use the contents list on page 5 to help you. It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

At the end of this booklet, there are details of other organisations that can help (see pages 131 to 136).

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

## Quotes

Throughout this booklet, we have included quotes from people affected by cancer. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. This includes Simon, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

## For more information

Our booklets **Having tests for prostate cancer** and **Understanding the PSA test** have more information about tests for prostate cancer, which you may find helpful. See page 126 for details of how to order them.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

# Contents

# ABOUT PROSTATE CANCER

---

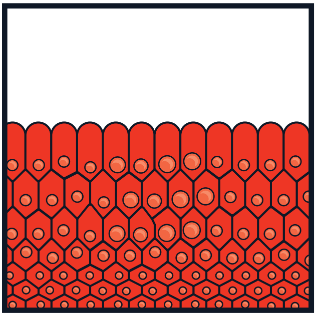
# What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can’t be repaired, it gets a signal to stop working and die.

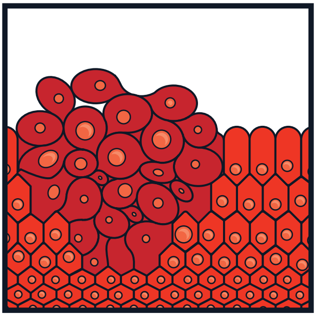
Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

**Normal cells**



**Cells forming a tumour**



A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system. When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

## The lymphatic system

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

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

If prostate cancer cells spread to the lymph nodes, they usually go to the nodes close to the prostate. In early prostate cancer, the cells have not spread to the lymph nodes.

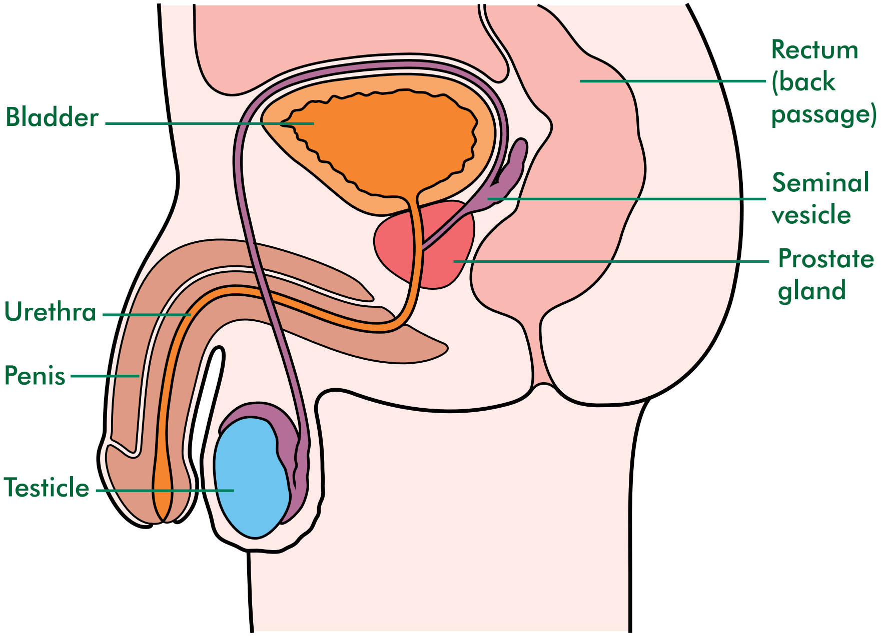
# The prostate

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

The prostate is below the bladder surrounding the first part of a tube called the urethra. The urethra carries pee (urine) from the bladder to the penis. The same tube also carries semen, which is the fluid containing sperm. Just behind the prostate is the back passage (rectum). There are also some lymph nodes (sometimes called glands) near the prostate – see page 9.

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

## Male reproductive system



## What does the prostate do?

The prostate produces a fluid that mixes with sperm (from the testicles) to make semen. The fluid is kept in a tube-shaped gland that sits behind the bladder. This gland is called the seminal vesicle. During sex, the muscle tissue helps force (ejaculate) prostate fluid and sperm into the urethra.

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

The prostate also produces a protein called prostate-specific antigen (PSA). This helps to make semen more watery. A blood test can measure PSA. This is called a PSA test. Doctors use it to help diagnose different prostate problems, including cancer. There is more information about this in our booklet **Understanding the PSA test** (see page 126).

# Early prostate cancer

Prostate cancer is the most common cancer in men in the UK. It is usually diagnosed in men over 65. Prostate cancer can happen in younger men, but it is uncommon in men under 50.

Early prostate cancer is when the cancer cells are only inside the prostate. The cancer has not spread through the capsule that surrounds the prostate (see page 10). Early prostate cancer is sometimes called **localised prostate cancer**. We call it early prostate cancer in this information.

Sometimes prostate cancer grows slowly. It may not cause any problems and not all cancers will need to be treated. Other prostate cancers grow faster and need to be treated to stop them spreading.

# Risk factors and causes

Doctors do not know the exact causes of prostate cancer. But there are risk factors that can increase a man's chance of developing it. Having one or more risk factors does not mean a man will get prostate cancer. Having no risk factors does not mean a man will not develop prostate cancer. Different risk factors may affect the risk of getting prostate cancer.

## Age

This is the strongest risk factor for prostate cancer. Men aged under 50 have a much lower risk of prostate cancer, although they can still develop it. The risk increases as men get older. More than half of all prostate cancers diagnosed in the UK are in men aged 70 and over.

## Ethnicity

Black men have a much higher risk of developing prostate cancer than white men. The reason for this is not clear, but it may be due to genetic factors. Black men are also usually diagnosed with prostate cancer at a younger age.

Prostate Cancer UK (see page 131 for contact details) provides an information pack for black men aged 45 and over who are concerned about their risk. It gives advice on talking to your GP about your risk of prostate cancer, to help you to decide whether to have tests.

Asian men have a lower risk of developing prostate cancer. The reason for this is unknown.

## Family history

Most men who get prostate cancer do not have a family history of it. Getting older is much more likely to be the significant risk factor.

But occasionally there may be a possible family link (inherited). Certain things make this more likely. For example, the more men in a family that have prostate cancer, the younger they were when diagnosed and the more closely related they are.

A man's risk of developing prostate cancer is higher if they have:

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

We inherit our genes from our parents. Doctors think 5% to 10% of prostate cancers are linked to inherited gene changes (mutations). But they do not think there is a specific prostate cancer gene. It is thought that changes in a few genes are involved.

In a small number of men, prostate cancer may be linked to changes in the breast and ovarian cancer genes BRCA1 and BRCA2. Men with the BRCA2 gene mutation may have up to a 5 times higher risk of prostate cancer compared with the general population. The BRCA1 gene may also increase risk, but this is not as clear. Prostate cancer risk is also higher in men with Lynch syndrome, also known as hereditary non-polyposis colorectal cancer (HNPCC). We have more information on our website.

Talk to your GP if you have a family history of cancer and are concerned about your prostate cancer risk. You might also find it helpful to read our booklet **Cancer genetics – how cancer sometimes runs in families**. See page 126 for details of how to order it.

## Body weight and diet

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

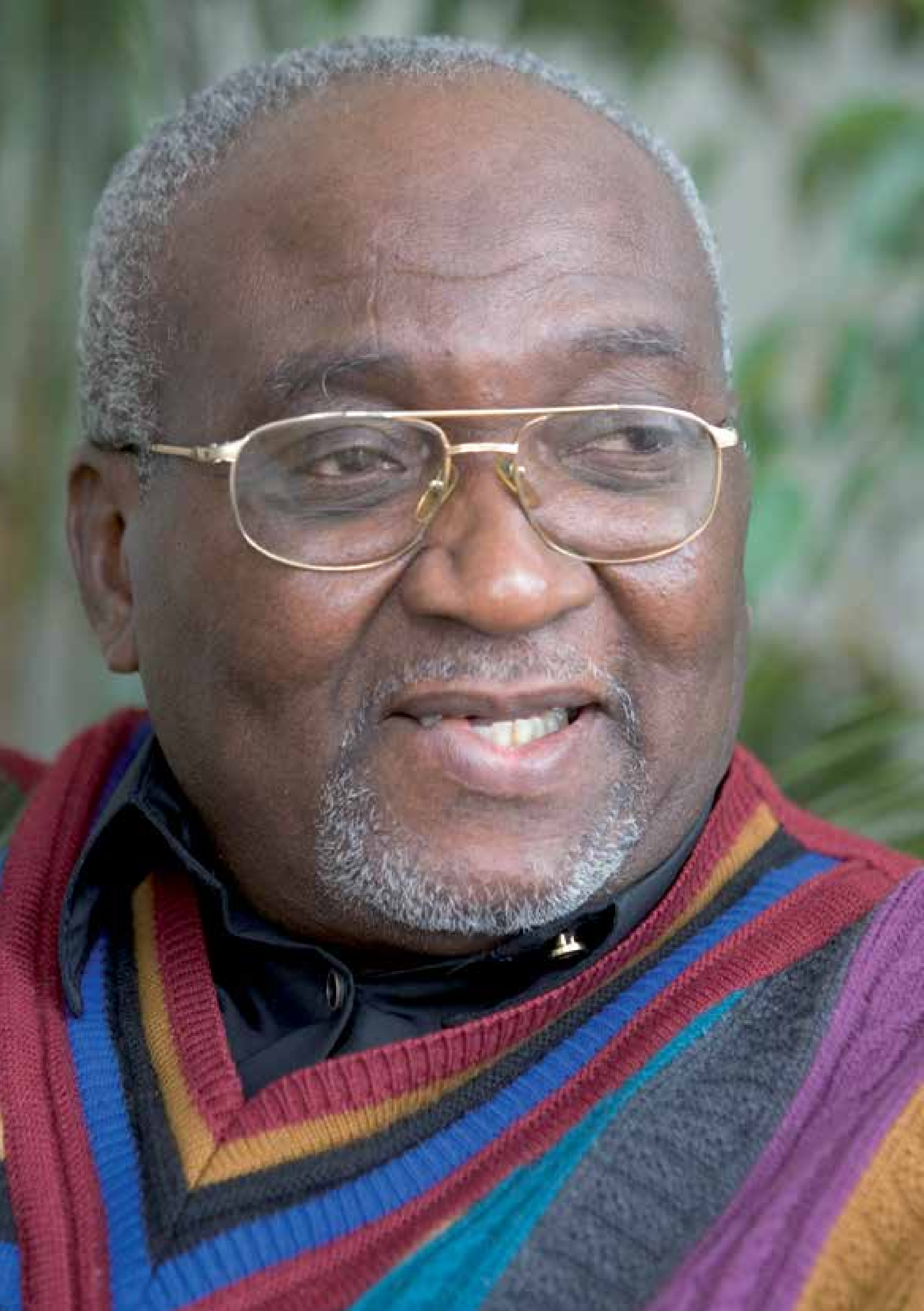
A diet high in animal fats may increase the risk of prostate cancer. This includes foods like red meat (such as beef, lamb and pork) and high-fat dairy products (such as butter, full-fat milk, cheese and cream).

A healthy, balanced diet is better for your general health. For most people, this includes:

- foods high in fibre (such as wholemeal bread, brown rice, oats, beans and lentils)
- lots of fruit and vegetables
- less red meat and less processed meat (such as sausages, burgers, bacon and ham)
- less fat and less sugar.

Eating a balanced diet and doing regular physical activity keeps you to a healthy weight. This may reduce your risk of certain types of cancers and other conditions, such as heart disease and diabetes.

You might find it helpful to read our booklets **Healthy eating and cancer** and **Physical activity and cancer** (see page 126).



# PROSTATE CANCER STAGING

# Staging of 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. We have more information in our booklet **Having tests for prostate cancer** (see page 126).

Your doctors also look at the grade of the cancer (see pages 24 to 25) and your PSA level (see page 11). This helps them to decide the risk group you are in to help plan your treatment.

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

# TNM staging

This gives information about the tumour, if it has spread to any lymph nodes, or to another part of the body (metastasis). T is for tumour, N is for nodes and M is metastasis.

## T Tumour

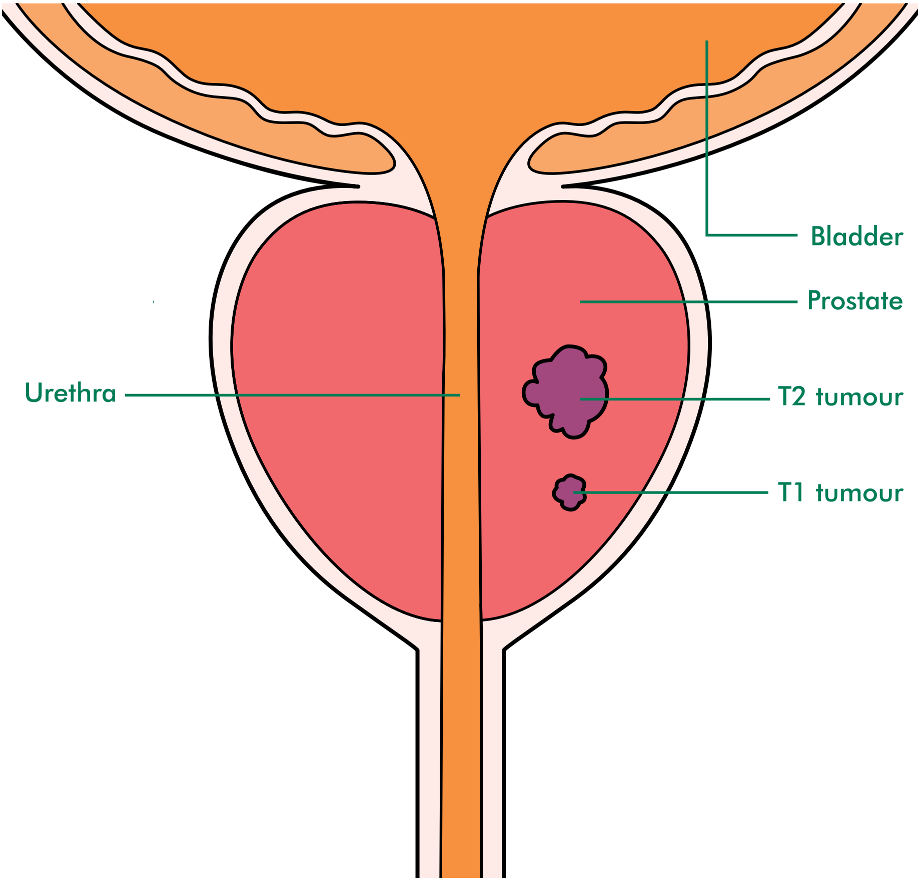
Doctors put a number next to the T to describe the size and spread of the cancer.

- **T1** means the tumour is contained in the prostate and is too small to be felt when a doctor does a rectal examination (see page 10) or seen on a scan. The cancer may have been diagnosed by a biopsy to check a raised PSA level. Or it may have been diagnosed by chance after an operation to remove part of the prostate to make peeing easier.
- **T2** means the tumour is still contained in the prostate, but your doctor can feel it when they do a rectal examination. T2 tumours are divided into:
    - **T2a** – The tumour is only in half of one of the two lobes of the prostate (see page 10).
    - **T2b** – The tumour is in more than one half of one lobe.
    - **T2c** – The tumour is in both lobes.

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

**T3** and **T4** tumours have started to spread outside the prostate and may be growing into tissues or organs close by. If the cancer has not spread to another part of the body, such as the bones, it is called locally advanced prostate cancer. When it has spread to another area, it is called advanced or metastatic prostate cancer. We have two booklets called **Understanding locally advanced cancer** and **Understanding advanced (metastatic) prostate cancer** – see page 126.

## Early prostate cancer (T1 to T2 tumour)



## N Nodes

**N0** means there is no cancer in the lymph nodes near the prostate, so early prostate cancer is always N0.

## M Metastasis

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

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

## The number staging system

This system brings together the different parts of the TNM staging system and gives it a number stage.

Early (localised) prostate cancer is either:

- stage 1 when the cancer is very small
- stage 2 when the cancer is a bit bigger.

It is contained to the prostate and has not spread outside it.

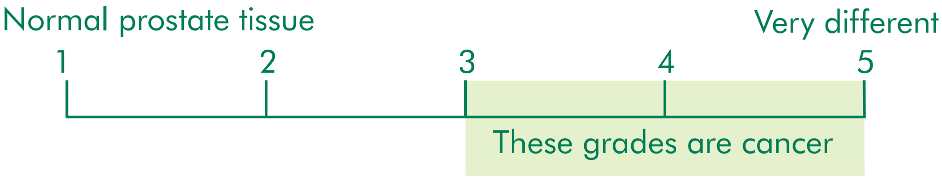
# Grading of prostate cancer

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

Gleason is the most commonly used grading system. It looks at the pattern of cancer cells in the prostate. There are 5 different patterns, graded from 1 to 5.

Grade 1 is very similar to normal prostate tissue, and grade 5 is very different to normal tissue. Only grades 3, 4 and 5 are cancer.



There may be more than one grade. The doctor examines all the samples taken at your biopsy. They find:

- the most common grade in the samples
- the highest grade in the samples.

They add these together to get your Gleason score. A Gleason score of 7 could be 3 + 4 or 4 + 3.

If your Gleason score is between 6 and 10:

- Gleason score 6 means the cancer is slow-growing and less likely to spread
- Gleason score 7 means the cancer is between a slow-growing and fast-growing cancer (intermediate grade)
- Gleason score 8 to 10 means the cancer is more likely to grow quickly and to spread (high grade).

## New grading system

This new system grades the cancer between 1 and 5, depending on your Gleason score. The lower the grade, the less likely the cancer is to spread. This helps your doctor to plan your treatment.

There are 5 Grade Groups:

- Grade Group 1 (Gleason score 6) is the lowest grade and not likely to spread.
- Grade Group 2 (Gleason score 3 + 4 = 7).
- Grade Group 3 (Gleason score 4 + 3 = 7).
- Grade Group 4 (Gleason score 8).
- Grade Group 5 (Gleason scores 9 and 10).

This system splits Gleason score 3 + 4 and 4 + 3, although they both equal a score of 7. If your most common grade is 3 rather than 4, you are in Grade Group 2. Men in Grade Group 3 may need more treatment than men in Grade Group 2.

Gleason scores 8 to 10 are split into Grade Group 4 and Grade Group 5. Grade Group 5 cancers are more likely to spread quickly than Grade Group 4 cancers.

## Prostate cancer risk groups

Early prostate cancer is also divided into risk groups. To work out your risk group, your doctor looks at the T stage of the cancer (see pages 21 to 22), your Gleason score and your PSA level. It helps you and your doctors decide on the best treatment choices for you.

### Low-risk prostate cancers

Low-risk prostate cancers are usually a **combination** of the following:

- Stage T1 to T2a
- Gleason score of 6 and under
- PSA level of 10 or under.

These cancers are unlikely to grow or spread for many years.

### Intermediate-risk prostate cancers

Intermediate-risk prostate cancers are usually **one** of the following:

- Stage T2b
- Gleason score of 7
- PSA level of 10 to 20.

These cancers are unlikely to grow for a few years.

### High-risk prostate cancers

High-risk prostate cancers are usually **one** of the following:

- Stage T2c
- Gleason score of 8 to 10
- PSA level of 20 or above.

These cancers are more likely to grow or spread in a few years.

Your doctor and specialist nurse can give you more information about your risk group.

# Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**

# TREATING EARLY PROSTATE CANCER

# Treatment overview

There are different treatments for early prostate cancer that can successfully treat the cancer. Your doctor and nurse will help you understand what these treatments involve and how they may affect your life. If possible, you may want to involve a partner or someone close to you in these talks. Deciding on your treatment can be difficult, but there is support to help you (see pages 34 to 36).

## Treatments

The main treatments include active surveillance, watchful waiting, surgery to remove the whole prostate, radiotherapy and hormonal therapy. Not everyone with early prostate cancer needs treatment straight away.

Your doctor will talk to you about the different things you should consider when making treatment decisions. Together, you can decide on the best treatment for you. This will depend on:

- your general health
- your age
- the Gleason score or cancer grade
- the risk group and stage of the cancer.

See pages 20 to 26 for more information about Gleason scores, staging, grading and risk groups.

## Delaying treatment

In some situations, doctors may ask you to think about not having treatment straight away. It means you can avoid treatment and its side effects until you need it. Some men may never need treatment.

There are different ways of delaying treatment:

### Active surveillance

Your specialist doctor monitors the cancer using tests. These tests include MRI scans, biopsies, and measuring your PSA level every 3 to 6 months. Your doctor might advise active surveillance (see pages 40 to 41) if either:

- the cancer is low risk
- you want to avoid immediate treatment.

If the cancer is not changing, you may avoid treatment and its side effects. If the cancer starts growing, you may have treatment to cure it straight away.

### Watchful waiting (watch and wait)

With watchful waiting (see pages 42 to 43), your doctors also monitor the cancer. But it does not involve regular scans or a biopsy unless the cancer grows and causes symptoms. It means you avoid treatment and its side effects for as long as possible.

Your doctor might advise this if either:

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

If the cancer starts growing or you get symptoms, your doctor will usually advise you to start hormonal therapy to control the cancer. But some older men may never need treatment for the cancer in their lifetime.

## Surgery

This is a major operation to remove the whole prostate, called a prostatectomy (see pages 44 to 52). The aim is to cure the cancer. Your specialist might ask you to think about this if the cancer is intermediate-risk or high-risk cancer (see page 26). You also need to be well enough to have a major operation.

## Radiotherapy

This uses high-energy x-rays to destroy the cancer cells. The aim is to cure the cancer. Radiotherapy is usually given externally (from outside the body). See pages 53 to 64 for more information about radiotherapy.

Some men have radiotherapy given internally (from inside the body). This is called brachytherapy (see pages 65 to 73). It is sometimes given on its own and sometimes given with external radiotherapy. Brachytherapy is not suitable for all prostate cancers. Your cancer doctor can discuss this with you.

## Hormonal therapy

Prostate cancer needs testosterone to grow. Hormonal therapy reduces the amount of testosterone in the body (see pages 74 to 79).

You may have hormonal therapy before, during or after radiotherapy, to make the treatment more effective. Or your doctor may advise having hormonal therapy on its own if either:

- you are older
- you have health problems that make having radiotherapy or surgery difficult.

## Other treatments

Some men may decide to have other treatments, such as cryotherapy (see pages 80 to 82) or high-intensity focused ultrasound (HIFU – see pages 83 to 87). These treatments are still being researched to see how effective they are, so you usually have them as part of a clinical trial (see pages 88 to 89). They are only suitable when the cancer is only on one side of the prostate.

We have a video that gives an overview of treatment for early prostate cancer on our website. You can watch it at **macmillan.org.uk/treatingearlyprostatecancer**

## How your treatment is planned

A team of specialists will meet to discuss the best possible treatment for you. This multidisciplinary team (MDT) will include:

- a surgeon (urologist) who specialises in operating on the prostate
- a cancer doctor (oncologist) who specialises in radiotherapy, hormonal therapy and chemotherapy treatments
- a specialist nurse who gives information and support
- a radiologist who analyses x-rays and scans
- a pathologist who advises on the type and extent of the cancer.

It may also include other healthcare professionals, such as social workers and physiotherapists.

## Talking about your treatment

After the MDT meeting, your specialist doctor and nurse will talk to you about your treatment options. Before this, you might find it useful to write down a list of your questions. It is a good idea to have a partner, family member or friend with you at the appointment. They can help you remember what was said and talk to you about it afterwards.

Your doctor will explain your treatment options and the aims. This should include:

- the benefits and disadvantages (risks and side effects) of different treatments
- other treatments that may be available
- what is likely to happen without the treatment.

They will explain different side effects and how they can be managed. They will help you make decisions about your treatment. If there is anything you do not understand, ask your doctor or nurse to explain it again. Cancer treatments can be complicated. It is also hard to take things in when you are feeling anxious. You may need to have more than one meeting with your doctor about your treatment.

> ‘My care team have been very open and good at communicating with me. It felt like they had taken the time to look at my case before offering me options.’
>
> **Simon**

## Deciding on your treatment

You and your doctor can decide on the right treatment plan for you. Your doctor is an expert in the most effective treatments, but you know best about your lifestyle and preferences.

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

- how different treatments and side effects will affect your everyday life
- how much certain side effects are likely to bother you
- if any other health conditions you have will affect how you can cope with certain treatments
- whether the cancer is likely to cause you problems over your lifetime
- how you would cope without having any treatment
- what treatment options you have if the cancer comes back.

You might find it helpful to read our booklet **Making treatment decisions** (see page 126).

## Delaying treatment

Your doctor may advise you to have active surveillance or watchful waiting rather than having treatment straight away. The risk group of the cancer can give your doctors more information about how likely the cancer is to grow (see page 26). But they cannot predict exactly what will happen.

Many prostate cancers grow very slowly and may never cause problems in a man’s lifetime. For some men, side effects such as erection difficulties or urinary incontinence may be worse than the effects of the cancer. Not having treatment straight away delays side effects for as long as possible. But you need to think about how you will cope with not having treatment.

## Choosing between treatments

Your doctor may ask you to choose between two treatments, for example surgery and radiotherapy. These treatments are equally effective.

Make sure you understand what each treatment involves and its advantages and disadvantages. You should also think about the immediate and long-term side effects. Your doctor or nurse may give you decision-making aids such as leaflets, videos, or web-based tools to help you decide.

You may want to think about how certain side effects are likely to affect you. It is also important to know about your treatment options if the cancer comes back. We have more information about advantages and disadvantages of individual treatments – see our individual treatment information on pages 40 to 89.

Prostate cancer treatments can affect your fertility. If this is a concern for you, talk to your doctor or nurse. You may be able to store sperm before treatment starts. There is more information in our booklet **Cancer treatment and fertility – information for men** (see page 126).

> ‘There were no fewer than 4 possible courses of treatment – 3 types of surgery, and radiotherapy coupled with hormonal therapy. I was being asked which I would prefer. That was an extremely difficult thing to do.’
>
> **Robert**

## Treatment effects on your sex life

For many men, the effects of treatment on their sex life and relationships is a major concern. Your doctor and nurse will explain the likely effects on your sex life (see pages 98 to 103). Try to let them know about your sexuality if you have issues you want to talk about. If you have a partner, it may help to bring them with you for support.

Talking about your sex life with your healthcare team can be uncomfortable. But your doctor and nurse are used to talking about these issues. There are different treatments and support available to improve sexual difficulties. Your doctor and nurse will explain these.

Prostate Cancer UK provides specific information and support for gay and bisexual men about the side effects of treatment and living with prostate cancer. See page 131 for details.

## Giving your consent

Your doctor or nurse will usually ask you to sign a form giving your permission (consent) for them to give you the treatment. They cannot give treatment without your consent. Make sure you fully understand what is involved (see pages 34 to 35) before you give consent.

Occasionally, people choose not to have treatment even though their doctor advises them to. Always tell your doctor or nurse about worries you have about treatment, so they can give you the best advice.

## Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.


BTOG
BTOG
BTOG

# Active surveillance

Some early prostate cancers grow very slowly and do not cause any symptoms. This means they may never need any treatment. In this situation, your doctor may offer you active surveillance. Active surveillance means you will not have treatment for prostate cancer straight away. Instead, you will have regular tests to check whether the prostate cancer is growing. Your doctor may monitor you and you may be offered some tests, such as:

- an MRI scan when you start active surveillance, if you have not had one before
- a rectal examination every 6 to 12 months
- blood tests every 3 to 6 months to check your PSA levels
- a prostate biopsy or an MRI scan after 1 year of active surveillance.

Our booklets **Having tests for prostate cancer** and **Understanding the PSA test** have more information about tests for prostate cancer. See page 126 for details of how to order them.

If the cancer is not getting any bigger or growing more quickly, it is safe to continue with active surveillance. Some men on active surveillance may never need treatment for prostate cancer.

If any of the tests show the cancer is starting to grow more quickly, your doctors will recommend surgery or radiotherapy (see pages 44 to 73) to try to cure the cancer.

## Advantages of active surveillance

- You can avoid or delay having treatment such as surgery or radiotherapy.
- You can avoid or delay the side effects of treatment.

## Disadvantages of active surveillance

- You may find it difficult to wait and see whether the cancer grows before starting any treatment.
- Very rarely, a cancer that has progressed during active surveillance may not be curable. But if this happens, the cancer can be controlled with long-term hormonal therapy.

# Watchful waiting

Some prostate cancers grow very slowly and may never cause any symptoms. For this reason, some men decide with their specialists to wait before starting any treatment. This is called watchful waiting. It is a way of avoiding treatment for as long as possible.

If you have early prostate cancer, you will usually be offered watchful waiting if you are not well enough to have radiotherapy or surgery. For example, this might be because you have another health condition. You may also be offered watchful waiting if you have chosen not to have radiotherapy or surgery.

You will not have as many tests as with active surveillance (see pages 40 to 41). Instead, you will see your doctor regularly – usually your GP. They will ask if you have any new symptoms, such as difficulty passing urine (peeing) or bone pain. If you do have symptoms, you may have regular blood tests to check your PSA levels. You may also have rectal examinations. Our booklets **Having tests for prostate cancer** and **Understanding the PSA test** have more information about tests for prostate cancer (see page 126).

If there is no sign that the cancer is getting bigger or growing more quickly, it is safe to continue with watchful waiting.

If you have any symptoms, or your PSA level rises, your GP will refer you back to the specialist at the hospital. They will usually recommend hormonal therapy (see pages 74 to 79). This will not cure the cancer, but it can help control it. In some men, hormonal therapy can control prostate cancer for many years.

## Advantages of watchful waiting

- You can avoid treatment such as surgery or radiotherapy, and related side effects.

## Disadvantages of watchful waiting

- You may find it difficult to cope with knowing the cancer is not being treated straight away.

# Surgery

Surgery to remove the prostate is called a radical prostatectomy. Before the operation, the surgeon (a urologist – see page 33) will explain what will happen and tell you about the possible side effects. They may also tell you about other treatments that may help in your situation, such as radiotherapy (see pages 53 to 73).

The aim of the surgery is to remove all of the cancer cells. It is usually only done when the cancer is contained in the prostate and has not spread to the surrounding area.

There are different types of radical prostatectomy.

## Open radical prostatectomy

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

## Laparoscopic radical prostatectomy

In this type of operation, your surgeon does not need to make a large cut. Instead, they remove the prostate using 4 or 5 small cuts (about 1cm each in length) in the tummy (abdomen). This type of surgery is also known as keyhole surgery.

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

### Robotic-assisted laparoscopic radical prostatectomy

This is when a laparoscopic radical prostatectomy can be assisted by a machine. Instead of the surgeon holding the tube with the camera (laparoscope) and the surgical equipment, they are attached to robotic arms. The surgeon controls the robotic arms, which can move very precisely. This means the surgeon is less likely to damage nerves that control erections and passing urine (urinary continence).

Surgeons need special training before they can do this type of surgery. This means it is only available in some hospitals in the UK. Your surgeon will tell you if robotic surgery is suitable for you and where the treatment is available.

## During surgery

During open or laparoscopic prostatectomy, the surgeon usually removes the seminal vesicle (the gland which helps to make semen – see page 10). They may also remove lymph nodes close to the prostate and check them for cancer cells. This depends on your risk of having cancer in the lymph nodes.

> ‘I was quite shocked when I was diagnosed. I just wanted to get rid of it, so I had the radical prostatectomy. The consultant explained it was an intricate operation and it could affect me in lots of different ways, but even so, I had the operation.’
>
> **Richard**

## After your prostatectomy

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

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

### Wound

If you have had an open prostatectomy, you will have a wound on your tummy or a wound between your scrotum and your back passage. If you have had a laparoscopic prostatectomy, you will have a few small wounds. You may have a small tube in the wound to drain any fluid coming from it. This is usually removed after a few days.

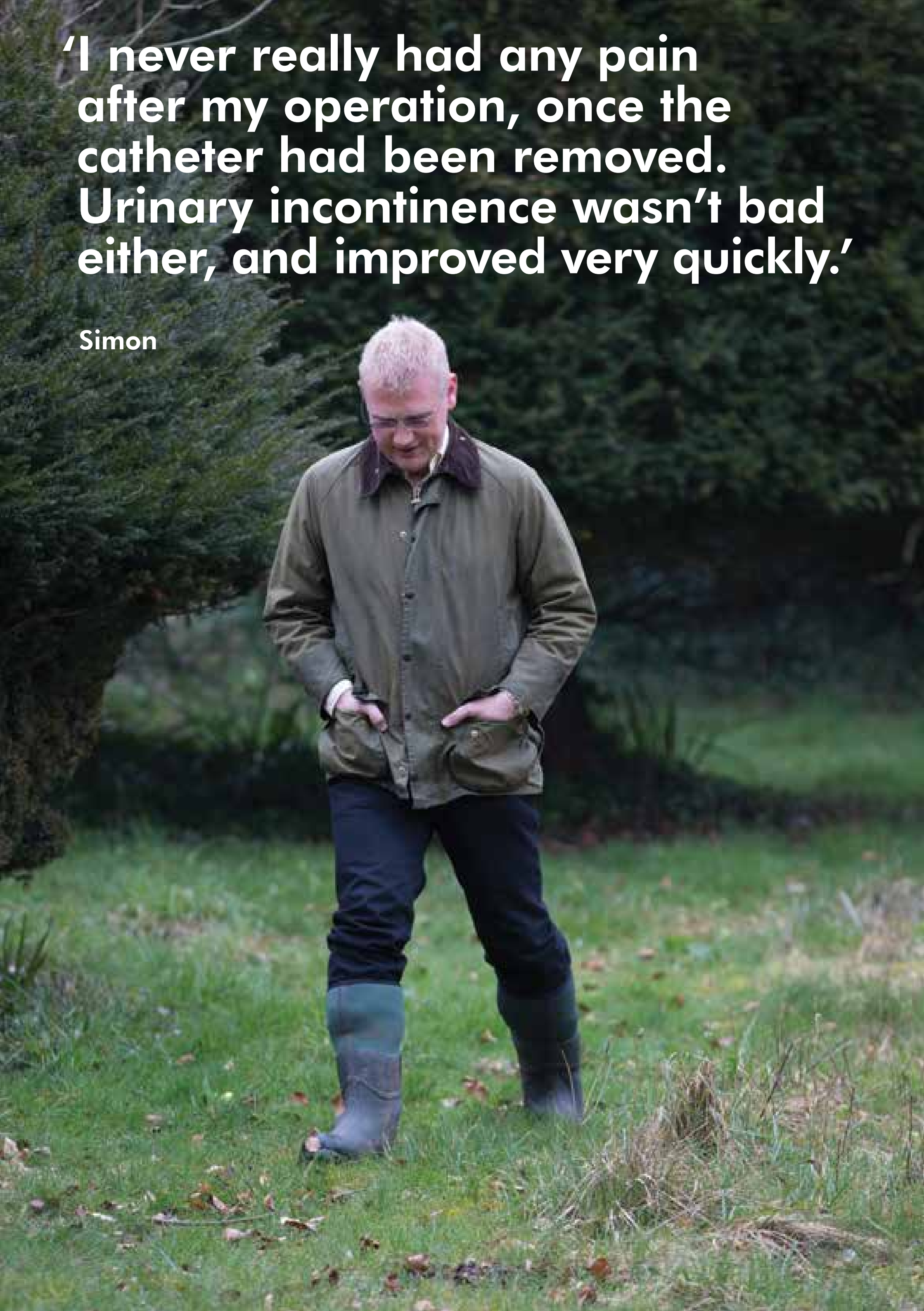
### Pain

You may have some pain or discomfort. This might continue for a few weeks, particularly when you walk. Taking painkillers regularly should help this. Let the staff on the ward know if you are still in pain.

### Catheter

You will have a tube (catheter) to drain urine from the bladder into a bag. Your catheter will usually stay in for a short while after you go home. This lets urine drain while the urethra heals (see page 10) and any swelling goes down. It can be removed at the outpatient clinic 1 to 3 weeks after the operation.

A district nurse can visit you at home if needed to make sure your catheter is working well. If you have any problems, contact your doctor, specialist nurse or the ward where you had your surgery as soon as possible.



> ‘I never really had any pain after my operation, once the catheter had been removed. Urinary incontinence wasn’t bad either, and improved very quickly.’

Simon

## Going home

If you had open surgery, you will probably be ready to go home after 3 to 7 days. If you had laparoscopic surgery, you can usually go home after 1 to 2 days.

Most men return to their normal activities 4 to 12 weeks after an operation for prostate cancer. It will depend on the type of surgery you have had (see pages 44 to 45). Men who have had robotic-assisted surgery usually recover faster and can get back to normal activities more quickly than men who have had open surgery.

Try to get plenty of rest and eat well. Do some light exercise, such as walking, to help build up your energy. You can slowly increase the amount you do.

If you think you might have any difficulties coping at home after your surgery, tell your nurse or social worker when you are admitted to hospital. They can arrange help for when you go home.

## Follow-up after surgery

After your prostate has been removed, your PSA level should drop to a level so low that it is not possible to detect it in the blood. Your PSA level will be checked about 6 to 8 weeks after surgery. This can help your doctors tell whether they removed all of the cancer.

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

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

# Side effects of a radical prostatectomy

## Erection problems

Surgery to the prostate can cause problems getting or keeping an erection (called erectile dysfunction or ED). This is caused by damage to the nerves and blood vessels close to the prostate that help you get an erection. Surgeons can do operations in a way that tries to protect these nerves and blood vessels. This is called a nerve-sparing technique. But this is only possible if the cancer has not spread outside the prostate. During the operation, if the surgeon thinks the nerves or surrounding structures have cancer in them, they will remove some or all of the nerves.

Whether you will have problems getting an erection after a nerve-sparing operation depends on different factors, such as:

- whether you had erection problems before treatment
- your age
- whether you have any other medical conditions, such as diabetes
- whether you are having treatment for high blood pressure
- whether the surgeon was able to spare some or all of the nerves.

You can ask your surgeon about your risk of ED.

Some men who have surgery may find their ability to have an erection slowly returns. But it may take 1 or 2 years for this to happen. It is less likely to return in men who have further treatment after surgery, such as hormonal therapy or radiotherapy.

We have more information about things you can try to help get an erection – see pages 98 to 103.

## Ejaculation

Men who have had their prostate removed can still have an orgasm, but there will be no ejaculation. This is called a dry ejaculation. A dry ejaculation may cause some discomfort at first, but this usually improves with time. Some men may pass a small amount of urine when they orgasm. Talk to your doctor or specialist doctor or nurse if you are having this problem. They may be able to give you some advice.

## Infertility

Having your prostate removed will affect your ability to have children. The prostate and seminal vesicle (see page 10) produce semen, which is normally mixed with sperm from the testicles. Removing the prostate means you will not be able to ejaculate any more. Although there is still sperm, it cannot get out of the body.

If you want to have children after your treatment, it may be possible to store sperm before your surgery. It is important to talk to your cancer doctor or specialist nurse about fertility before starting treatment (see page 104). Think about the questions you want to ask, so you can get all the information you need. If you have a partner, it is usually a good idea to include them too.

It can be upsetting to hear that you will longer be able to have children. Some men find it helpful to talk things over with a partner, family or friends. Others might prefer to talk to a trained counsellor. Your GP or cancer specialist can arrange this for you. Many hospitals also have specialist nurses who can offer support. And fertility clinics usually have a counsellor you can talk to.

Talking to other men in a similar situation may help you feel less isolated. Some organisations can arrange this for you as well as providing specialist advice and counselling – see pages 131 to 136. Or you can talk to people online. Our Online Community is a good place to talk to other men who may be in a similar situation – visit **community.macmillan.org.uk** You can also talk to one of our cancer support specialists on **0808 808 00 00**.

## Bladder problems

Urine leaking from the bladder (urinary incontinence) is a less common side effect of having the prostate removed. Most men have some incontinence when their catheter is first removed. This usually improves within a few weeks or months of having your operation. You will be encouraged to do pelvic floor exercises to strengthen the pelvic floor muscles. You can do these at home. The Bladder and Bowel Community can give you more information on how to do them – see page 131.

A small number of men may continue to be incontinent when they cough, sneeze or exercise. This is called stress incontinence. It is very rare to be completely incontinent. If you are having problems with incontinence, talk to your doctor or nurse. They can refer you to a continence team, who can give you advice about coping with this problem. If treatments for stress incontinence are not successful, you may be able to have an operation.

Another less common side effect of surgery is scarring of the bladder or urethra (see page 10). The urethra is the tube that runs from the bladder to the tip of the penis. It takes urine away from the bladder. Scar tissue can make the urethra narrow, which makes passing urine difficult. This means that urine builds up in the bladder and starts to overflow. This problem can usually be treated with a small operation that opens up the urethra. If you are having problems peeing after your operation, talk to your specialist doctor or nurse.

### Macmillan toilet card

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.

You can order this card by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**

## Advantages of a prostatectomy

- If the cancer has not spread outside the prostate, removing it may cure the cancer and you will not need any more treatment.
- If the cancer comes back, you will still be able to have further treatment.
- If you had urinary symptoms before surgery, these may improve after surgery.

## Disadvantages of a prostatectomy

- There may be a small risk of problems after the surgery, such as bleeding or infection.
- Surgery may cause long-term problems with erectile dysfunction and incontinence.
- Removing the prostate means you will no longer be able to have children.

# Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells. The aim of radiotherapy for early prostate cancer is to destroy all the cancer cells and cure the cancer. Doctors call this radical radiotherapy. At the same time, they try to make sure radiotherapy causes as little harm as possible to healthy tissue and organs close by. These include the bladder, back passage (rectum) and bowel.

Radiotherapy for prostate cancer can be given in different ways:

- External-beam radiotherapy – radiotherapy is given from outside the body (externally) from a radiotherapy machine.
- Brachytherapy – radiotherapy is given from inside the body (internally).

External-beam radiotherapy is the most common way of giving radiotherapy for early prostate cancer. If you have brachytherapy, it may be given on its own or along with external radiotherapy.

Your cancer doctor may advise you to have hormonal therapy for up to 6 months before radiotherapy (see pages 74 to 79). Hormonal therapy can shrink the cancer, which helps make radiotherapy more effective. You may be given hormonal therapy before, during and after radiotherapy.

If you smoke, you should try to stop. Not smoking during and after radiotherapy can make treatment more effective and reduce the side effects.

Many hospitals provide help or advice on how to quit smoking. Ask your cancer doctor, radiographer or specialist nurse if your hospital provides this service. If they do not, your GP, a pharmacist or an organisation such as Smokefree can help – see page 134. We have a booklet called **Giving up smoking** (see page 126).

## External-beam radiotherapy for early prostate cancer

You have external-beam radiotherapy as an outpatient in the radiotherapy department. Radiotherapy is given using a machine that is like a big x-ray machine (see the photo on page 57). This is called a linear accelerator (often called a LINAC).

You usually have it as a series of short, daily treatments. The treatments are given from Monday to Friday, with a rest at the weekend. Your course of treatment may last for 4 to 8 weeks. Radiotherapy is not painful, but you will need to lie still while you have it.

Some men have radiotherapy over 4 weeks instead of over 7 weeks. The total dose of radiation is the same for both. But when it is given over 4 weeks, the dose for each treatment session is higher. Doctors call this hypofractionation. Both are effective treatments. Your cancer doctor will recommend the best timing and way for you to have your radiotherapy.

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

## Types of external-beam radiotherapy

There are different types of external-beam radiotherapy. They aim to treat the cancer while protecting healthy tissue. This reduces side effects.

You usually have either conformal radiotherapy or intensity-modulated radiotherapy (IMRT). They are both effective treatments for prostate cancer:

- Conformal radiotherapy – Uses specially shaped radiation beams, so they match the shape of the cancer. This reduces damage to surrounding healthy tissue.
- Intensity-modulated radiotherapy (IMRT) – Shapes the radiation beams and allows different doses of radiotherapy to be given to different areas. Lower doses are given to healthy tissue, which reduces the risk of damage.

Other types of radiotherapy are used less commonly:

- Image-guided radiotherapy (IGRT) – This is usually done alongside IMRT. Images are taken before or during radiotherapy that show the size, shape and location of the tumour. These are used to make changes to the treatment area.
- Stereotactic ablative radiotherapy (SABR) – This allows large doses of radiotherapy to be given to small areas very precisely, so you need fewer treatments. Different machines can be used to give SABR. It is only available in a research trial for prostate cancer (see pages 88 to 89).

There is more information about the different types of radiotherapy in our booklet **Understanding radiotherapy** (see page 126).

## Planning external-beam radiotherapy

Your cancer doctor (oncologist) plans your radiotherapy carefully to make sure it is as effective as possible. On your first visit, you will have a planning CT scan. The scan helps them work out the exact dose and area of your treatment.

Before your scan, you may need to follow a special diet or take medicine to empty your bowel. You may also need to drink water to fill your bladder. This is to get very clear CT pictures to help plan your treatment.

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

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

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

Some men have tiny gold grains put into their prostate gland using an ultrasound scan. They act as markers that show the position of the prostate to help your cancer doctor plan each session of treatment. Having these markers can help reduce side effects and any possible damage to organs close to the prostate.

A radiotherapy machine

## Treatment sessions

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

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

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

> ‘My radiotherapy was a strange experience, since in spite of lying on a couch under an impressive whizzing machine behind thick doors, I felt absolutely nothing.’
>
> **Ray**

## Side effects of external-beam radiotherapy

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

Your doctor, nurse or radiographer will talk to you about this. They will explain what to expect and give you advice on what you can do to manage side effects. Always tell them about your side effects. There are usually things they can do to help. We list the common side effects here, but you may not get all of these.

We have more detailed information about pelvic radiotherapy in our booklet **Pelvic radiotherapy in men – managing side effects during treatment** (see page 126).

### Tiredness

Radiotherapy causes tiredness, especially towards the end of treatment. It may last for a couple of months or longer after treatment has finished. Make sure you get plenty of rest. But try to balance this with regular physical activity, such as short walks. This will help give you more energy.

There is more information in our booklets **Coping with fatigue** and **Physical activity and cancer** (see page 126).

## Effects on the skin

The skin in the treated area may become red (if you have light skin) or darker (if you have dark skin). It may also become dry, flaky, and itchy. Sometimes the skin around the back passage (rectum) and scrotum becomes moist and sore. The radiographer or your specialist nurse will tell you how to look after the skin in the treated area. They can prescribe a cream or dressings and painkillers if you need them. Always tell them if your skin is sore or you have other changes.

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.

## Effects on the bladder

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

- feel you want to pass urine (pee) more often
- have a burning feeling
- have urgency when you pass urine.

Your doctor can prescribe medicines to help. Drinking 2 to 3 litres (3½ to 5½ pints) of fluids a day can help. Avoid drinks containing caffeine and alcohol.

These side effects usually disappear slowly a few weeks after treatment has finished.

Occasionally, men may have difficulty passing urine and need to have a tube put into the bladder to drain urine (urinary catheter). Rarely, some men may have some leakage of urine (incontinence). Let your nurse or radiographer know if this happens.

Some men who had urinary problems when they were diagnosed may find these improve a while after their radiotherapy finishes.

### Effects on the bowel

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

If you have diarrhoea, drink at least 2 to 3 litres (3½ to 5½ pints) of fluids a day. Avoid caffeine and alcohol. Your nurse or radiographer may advise you to make some changes to your diet during treatment, such as eating less fibre.

## Possible late effects of external-beam radiotherapy

Some men may have side effects that do not improve, or side effects that happen months to years after radiotherapy finishes. These are called long-term or late effects. Your doctor or nurse will explain these to you. There are different ways late effects of pelvic radiotherapy can be managed.

Our booklet **Managing the late effects of pelvic radiotherapy in men** has more information (see page 126).

### Erection problems

Radiotherapy for prostate cancer can cause problems getting or keeping an erection. This is called erectile dysfunction (ED). Your age and whether you are taking hormonal therapy can also affect how likely you are to get ED.

ED may not happen straight after treatment. It can develop slowly over 2 to 5 years. Ask your cancer doctor about your risk of ED. If you develop ED, there are different treatments that can help.

After radiotherapy and brachytherapy, some men ejaculate little or no semen.

### Infertility

Radiotherapy to the prostate may cause permanent infertility. Some men may find this difficult to cope with. If you are worried, talk to your cancer doctor. You may be able to store sperm before treatment starts.

There is more information in our booklet **Cancer treatment and fertility – information for men** (see page 126).

### Bowel and bladder problems

Some men may have bowel or bladder changes because of radiotherapy. For example, blood vessels in your bowel and bladder may become more fragile. This may cause blood in your urine or from the back passage (bottom). If you notice any bleeding, always tell your doctor so they can check it out.

Let them know about any bowel or bladder symptoms you have. They can give you advice and may do some tests. You may also find it helpful to contact the Bladder and Bowel Community for support (see page 131).

Bowel changes can include diarrhoea, wind or constipation. Rarely, some men have difficulty controlling their bowels and may have some leakage (faecal incontinence). These symptoms can often be managed with medication and changes to your diet. If the problems do not improve, you can ask to be referred to a bowel specialist (a gastroenterologist or bowel surgeon).

The symptoms of bladder irritation that happen may not stop completely. Rarely, men get leakage of small amounts of urine (incontinence). Your doctor can arrange for you to see a specialist continence nurse or physiotherapist for advice.

## Macmillan toilet card

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.

You can order this card by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**

## PSA levels after external radiotherapy

After radiotherapy it can take time for your PSA level to drop. It usually goes down gradually. It may not get to its lowest level until about 18 months or longer after treatment. Your doctor and specialist nurse can give you more information about this.

## Advantages and disadvantages of external-beam radiotherapy

Radiotherapy and radical prostatectomy (see pages 44 to 52) are both treatments that may cure early prostate cancer. They are equally effective in treating the cancer.

To choose the treatment that is best for you, it can help to look at the different advantages and disadvantages of each one. You can then make your decision in partnership with your doctor. See page 36 for more information about choosing between treatments.

### Advantages of external-beam radiotherapy

- You do not need an operation or a general anaesthetic, which may have risks.
- You can carry on doing most of the daily things you usually do.
- Urinary problems may happen less often than after surgery.

### Disadvantages of external-beam radiotherapy

- You have to go to hospital for 4 to 8 weeks, Monday to Friday, as an outpatient.
- It can cause the side effects listed here. And some men may get bowel late effects.
- It may be some time before doctors know if treatment has been successful.
- If the cancer comes back after radiotherapy, it is more difficult to have surgery to remove the prostate.

## Brachytherapy for early prostate cancer

Brachytherapy (internal radiotherapy) gives high doses of radiation directly to the prostate. Areas close by, such as the rectum and the bladder, get a much lower dose.

It can only be used for certain types of early prostate cancer and is not suitable for men who have difficult urinary problems.

Brachytherapy can be given:

- on its own, usually to treat low-risk prostate cancer (see page 26)
- before or after external-beam radiotherapy to make treatment work better, usually for medium-risk to high-risk prostate cancer
- with hormonal therapy (see pages 74 to 79), or with hormonal therapy and external radiotherapy.

Brachytherapy is only given in specialist hospitals in the UK. There are two ways of giving it:

- Radioactive seed implants or low-dose rate (LDR) brachytherapy – Small, radioactive metal 'seeds' are placed in the prostate and stay there permanently. They slowly release radiation until it has been used up. The radiation will be completely gone after 6 months.
- High-dose rate (HDR) brachytherapy – Thin tubes are placed in the prostate. They are attached to a machine that sends radioactive material into the tubes for a set time. HDR is usually given with external radiotherapy.

There may be some differences in how each hospital gives brachytherapy. Your doctor or nurse will explain what will happen. They will usually give you written information about:

- brachytherapy
- how you prepare for it
- possible side effects (see pages 70 to 71).

You usually have antibiotics before brachytherapy to help prevent infection. You may also be given tablets to help you pass urine more easily.

## Radioactive seed brachytherapy

This is the most common type of brachytherapy for early prostate cancer. You may need two separate hospital visits, or you may have more than one treatment on the same day.

You will have a general or a spinal anaesthetic (injection of painkillers into the spine) to have radioactive seed brachytherapy. If you have a spinal anaesthetic, you will be awake but will not feel any pain.

### Planning

Your doctor passes an ultrasound probe into the back passage (rectum) to take pictures of the prostate. This helps them plan how many radioactive seeds are needed and where they should be placed.

Before the scan, you may need to have a special diet for 24 hours. You may also have a small amount of liquid passed into your rectum (enema). This makes sure your bowel is empty, so the ultrasound picture is clear.

### Implanting the seeds

The doctor can place the seeds into the prostate (implanted) on the same day or a few weeks later under a general anaesthetic.

The doctor passes an ultrasound probe into the rectum to show your prostate and help guide them. They pass a special needle through the skin between the scrotum and back passage, to insert the seeds into the prostate.

You can usually go home on the same day, but someone will need to take you. You will not be able to drive, because of the anaesthetic.

### After treatment

All the radioactivity from the seeds is absorbed from inside the prostate. So it is safe for you to be around other people. As a precaution, you need to avoid long periods of close contact with pregnant women and children for the first few months after treatment. It is safe for children to be in the same room as you. You can hold or cuddle them for a few minutes each day. Your doctor or nurse will give you more information about this.

After brachytherapy, you need to avoid heavy lifting or brisk physical activity for 2 to 3 days. The area between your legs can feel bruised and inflamed for a few days. Your doctor can prescribe painkillers to take.

### Sex

Your doctor will advise you to use a condom during sexual activity for at least the first few weeks after the seeds have been put in. There is a slight chance of a single seed being passed in your semen when you ejaculate. Double-wrap used condoms and dispose of them in a dustbin.

If you identify as gay or bisexual you can ask your doctor or nurse about any possible risk to your partner during sex.

Your semen may be coloured black or brown for a short time. This is caused by some bleeding during the procedure. It is harmless.

> ‘I was diagnosed with prostate cancer 10 years ago now and was one of the first people to be treated with brachytherapy at my hospital. It’s like having radioactive seeds planted in your prostate where the tumour is. The side effects of treatment tailed off after 3 months.’
>
> **Harry**

## HDR brachytherapy

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

### Having the tubes put in

Your doctor passes an ultrasound probe into the back passage (rectum) to take pictures of the prostate. This helps your doctor plan the number of tubes needed and where they should be placed.

Your specialist puts the tubes that deliver the brachytherapy into the prostate. They pass them into the prostate through the skin between the scrotum and back passage. Your doctor may also put a thin tube into the bladder to drain urine (catheter). This prevents any swelling of the prostate stopping you passing urine. They remove the catheter before you go home.

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

### Having HDR

The nurses take you to a treatment room that has the HDR machine. They attach the tubes to a machine which sends the radioactive material into the tubes going into the prostate. A computer monitors how long the radioactive material stays in place for. The treatment takes up to an hour.

The tubes can be uncomfortable, and you must stay in bed lying down while they are in place. The nurses will give you painkillers to take. After HDR brachytherapy is finished, the radioactive material is returned to the machine and your doctor removes the tubes.

If you need more than one treatment, the tubes are left in place in between treatments. Some men need 2 or 3 treatments over 24 hours.

### After treatment

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

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

## Side effects of brachytherapy

Brachytherapy causes similar side effects to external-beam radiotherapy (see pages 59 to 62). If you have brachytherapy on its own, some side effects may be less troublesome. If you have it with external-beam radiotherapy, side effects may be more severe.

Some side effects may take several weeks to develop and may last for longer.

### Erection problems

Brachytherapy for prostate cancer can cause problems getting and keeping an erection. This is called erectile dysfunction (ED). Ask your cancer doctor about your risk of ED. If you develop ED, there are different treatments that can help.

After brachytherapy, some men ejaculate little or no semen.

### Infertility

Having brachytherapy on its own can still cause infertility (see page 104), but the risk may be lower than with external-beam radiotherapy. If you are worried about your fertility, talk to your cancer doctor. You may be able to store sperm before treatment starts.

## Bowel problems

Brachytherapy may cause some bowel problems for a few weeks after treatment. But it is less likely than external-beam radiotherapy to affect the bowel and cause late bowel effects (see pages 59 to 62).

## Effects on the bladder

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

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

You may also:

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

Drinking plenty of water and avoiding caffeine and alcohol will help improve your symptoms. With HDR brachytherapy, these symptoms should improve after a few weeks. If you had radioactive seed brachytherapy, it may take longer. Your symptoms will improve over the following months as the seeds lose their radioactivity.

## Not being able to pass urine

Brachytherapy may cause swelling of the prostate. This may make it difficult to pass urine. If this happens, you may need to have a catheter put in your bladder until the swelling goes down.

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

## Advantages and disadvantages

If you have a low-risk cancer, you may be asked to decide between external-beam radiotherapy and brachytherapy. They are both effective treatments for certain men with early prostate cancer.

### Advantages of brachytherapy

- You usually only need 1 or 2 visits to hospital, rather than weeks of external-beam radiotherapy treatment.
- Your recovery is quick.
- Bowel side effects are less common than with external-beam radiotherapy.

### Disadvantages of brachytherapy

- You need a general or a spinal anaesthetic.
- With radioactive seeds, you need to avoid close contact with children or pregnant women for a couple of months after treatment.
- Bladder side effects may be more severe than with external-beam radiotherapy.

# Hormonal therapy

Prostate cancer needs the hormone testosterone to grow. Testosterone is mainly made by the testicles. Hormonal therapies lower your testosterone levels or stop it reaching the prostate cancer cells.

Testosterone is important for:

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

## Hormonal therapy with radiotherapy

Doctors often advise having hormonal therapy along with radiotherapy (including brachytherapy), to make treatment more effective (see pages 53 to 73.) This is usually if you have intermediate-risk or high-risk early prostate cancer. You may also have hormonal therapy before treatment with HIFU (see pages 83 to 87).

You may have hormonal therapy during radiotherapy and either:

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

Your doctor will advise when and how long you should have the hormonal therapy for. If you have intermediate-risk prostate cancer, you may have hormonal therapy for up to a few months after treatment finishes. Men with high-risk prostate cancer may be advised to have hormonal therapy for 2 to 3 years after radiotherapy finishes.

## Hormonal therapy on its own

If your doctors are using the watchful waiting approach (see pages 42 to 43) and the cancer starts to grow, you may have hormonal therapy on its own.

Some men decide to have hormonal therapy on its own instead of with surgery or radiotherapy. Unlike these treatments, hormonal therapy on its own will not get rid of all the cancer cells. Doctors do not usually advise this. But it may be suitable if you:

- are not well enough to have surgery or radiotherapy
- do not want these treatments.

Hormonal therapy can slow down or stop the cancer cells growing for many years. Not having surgery or radiotherapy means you avoid the side effects of these treatments. Hormonal therapy can also cause side effects (see pages 78 to 79). It is important to talk to your doctor or nurse about it before you decide.

# Types of hormonal therapy

There are different types of hormonal therapy that may be used. Your doctor or nurse will explain the drug that is most suitable for your situation.

## LHRH agonists

The pituitary gland in the brain makes a hormone called luteinising hormone (LH). This hormone tells the testicles to make testosterone. LHRH agonists interfere with this action and stop the testicles making testosterone. You have them as an implant injection or an injection under the skin.

The commonly used LHRH agonists are:

- goserelin (Zoladex®, Novgos®)
- leuprorelin (Prostap®, Lutrate®)
- triptorelin (Decapeptyl®, Gonapeptyl Depot®).

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

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

Leuprorelin and triptorelin are given as an injection under the skin or into a muscle. You have these monthly, or every 3 to 6 months.

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

## Anti-androgen drugs

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

Some men may have anti-androgen drugs with radiotherapy instead of having an LHRH agonist with radiotherapy. Or you may have an anti-androgen before and after the first injection of a LHRH agonist, to prevent any symptoms getting temporarily worse (tumour flare).

Anti-androgen drugs include:

- bicalutamide (Casodex®)
- flutamide.

We have more information about the drugs used in hormonal therapy on our website. Visit **macmillan.org.uk**

# Side effects of hormonal therapy

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

## Common side effects

Common side effects include the following:

- Erection difficulties (called erectile dysfunction or ED) and reduced sex drive. This usually improves after you stop treatment, but it may take a few months. If you have ED, there are drugs and treatments that may help.
- Hot flushes and sweats. These may reduce as your body adjusts to hormonal treatment. They usually stop completely 3 to 6 months after treatment finishes.
- Tiredness and difficulty sleeping. This is common, and hot flushes may make sleeping difficult. Regular physical activity can help reduce tiredness. We have more information about physical activity and cancer – see page 96.
- Mood changes. Talking to someone close to you or a counsellor may help.

## Other side effects

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

Other possible side effects include the following:

- Weight gain (especially around the middle) and loss of muscle strength. Regular physical activity and a healthy, balanced diet can help manage this.
- Breast swelling or tenderness. This is most common with flutamide and bicalutamide. Some men have low-dose radiotherapy to their chest before treatment to prevent this. If you are taking bicalutamide, another option is to take a hormonal drug called tamoxifen to reduce breast swelling.
- Bone thinning (osteoporosis). The risk of this is increased with long-term hormonal treatment. You may have a scan to check your bones before you start treatment. Regular weight-bearing exercises such as walking, dancing, hiking or gentle weight-lifting can help keep your bones healthy. Your doctor may give you advice on diet and exercise. They may advise you to take calcium and vitamin D tablets. They may also talk to you about taking bone-strengthening drugs called bisphosphonates or a drug called denosumab (Prolia®).
- An increase in the risk of heart disease and diabetes. Not smoking, being physically active, eating healthily and keeping to a healthy weight can help reduce these risks. We have more information about heart disease and diabetes, as well as stopping smoking and eating healthily – see page 126 to order it.

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

# Cryotherapy

Cryotherapy is a treatment for early prostate cancer or prostate cancer that has come back after radiotherapy. It is suitable for very small prostate cancers that are contained in the prostate. It cannot be used for cancers near the outer edge of the prostate.

Cryotherapy is not widely available. It is given as part of a clinical trial, so it is only available in some hospitals in the UK.

Cryotherapy is usually given under a general anaesthetic. This means you will be asleep during the treatment. If you cannot have a general anaesthetic, you will have spinal anaesthetic. This will numb the lower half of your body, so you will not be able to feel anything. You may also be given a sedative to make you feel relaxed and sleepy.

Cryotherapy destroys cancer cells by freezing them with a special gas. A doctor gently passes thin needles through the skin behind the scrotum (perineum). The doctor also uses an ultrasound probe through the back passage (rectum). This helps them get a good view of the prostate and make sure the needles are going into the right place. The gas is then passed through the needles into the area of the prostate where the cancer is.

Cryotherapy can be used to treat the whole prostate when there might be cancer in more than one area, so that all areas of cancer are treated.

But it may also be used for men who only need treatment to one small area of cancer in the prostate. Doctors call this focal therapy. It takes less time than whole-prostate treatment. It may also cause fewer side effects, because less of the healthy tissue is damaged.

Men who have had this treatment for early prostate cancer can have radiotherapy or surgery if the cancer comes back (see pages 44 to 73).

## Side effects of cryotherapy

### Problems peeing (passing urine)

After cryotherapy, some men may have problems peeing. To prevent this, a tube (catheter) is put into the bladder through the skin in the tummy (abdomen) to drain urine. This is left in for 1 to 2 weeks. Then you have it removed as an outpatient.

### Pain

You may have some pain in your lower tummy or back passage (rectum). You will be given painkillers for this.

### Swelling and numbness

You may have some swelling, numbness or tingling around the penis and scrotum. This happens 1 to 2 weeks after the cryotherapy. It will slowly improve over a few months.

## Possible late effects of cryotherapy

### Erection problems

Cryotherapy for prostate cancer can cause problems getting an erection (called erectile dysfunction or ED). Your age and taking hormonal therapy can also affect this.

ED problems may not happen straight after treatment. They can develop slowly after treatment, over 2 to 5 years. Talk to your cancer doctor about your risk of ED. There are different treatments that can help if you have ED.

## Urinary incontinence

This is when urine leaks from the bladder. Most men have some incontinence when their catheter is first removed. This usually improves over a few months after finishing treatment. You will be encouraged to do exercises to strengthen the pelvic floor muscles. You can do these at home. The Bladder and Bowel Community can give you more information on how to do these exercises (see page 131).

Because cryotherapy is still quite a new treatment, we do not know if there are any other long-term side effects yet.

# High-intensity focused ultrasound (HIFU) treatment

This is sometimes used as a treatment for early prostate cancer or prostate cancer that has come back after radiotherapy. It is given as part of a clinical trial, so it is only available in some hospitals in the UK.

HIFU treatment is given under a general or spinal anaesthetic. A probe is gently passed into the back passage (rectum). The probe makes a high-energy beam of ultrasound. This heats the affected area of the prostate and destroys the cancer cells. The probe is surrounded by a cooling balloon. This means the high-energy beams are only given to the areas with cancer in them and normal prostate tissue is protected.

## Focal therapy

HIFU can be given to the whole prostate when there might be cancer in more than one area, so that all areas of cancer are treated.

But it may also be used for men who only need treatment to one small area of cancer in the prostate. Doctors call this focal therapy. It takes less time than whole-prostate treatment. It may also cause fewer side effects, because less of the healthy tissue is damaged.

You may have an MRI scan and several samples of prostate tissue taken (called a template biopsy). This will give the doctors a clear picture of where the cancer is in the prostate.

You may also have a prostate biopsy. This gives your doctor more information about the grade of the cancer (see pages 24 to 25). Areas of cancer that are shown to have a high risk of growing quickly will be given focal HIFU. But if the biopsy shows some areas to be very slow-growing, these may not be treated. This may mean you have fewer side effects.

After HIFU treatment, you will have regular PSA blood tests (see page 11). If your PSA level is still high, you will be offered a different type of treatment, such as radiotherapy or surgery (see pages 44 to 73).

## Side effects of HIFU

### Urine infections

Some men may get a urine infection after this treatment. You should contact your doctor if you:

- have a high temperature
- have a burning feeling when you pass urine (pee)
- have urine that is dark in colour or cloudy
- need to pass urine more often than usual.

Your doctor will usually prescribe antibiotics if you have a urine infection.

## Urinary retention

This happens when you cannot empty your bladder properly after your catheter is removed. HIFU can cause the prostate to swell. This may block the tube from the bladder that urine passes through (urethra). If your urine flow is weak or very slow, you should talk to your doctor or nurse.

If you are not able to pass urine at all, contact your doctor or nurse straight away or go to your nearest emergency department (A&E). Your bladder may need to be drained using a catheter.

## Testicle infection

You may get an infection in the testicle or in the tubes that carry sperm from the testicle. You should talk to your doctor or nurse if your testicles are:

- painful
- swollen
- tender to touch.

Testicle infections can usually be treated with antibiotics.

# Possible late effects of HIFU

## Erection problems

HIFU for prostate cancer can cause problems getting an erection (called erectile dysfunction or ED). Your age and taking hormonal therapy can also affect this.

ED problems may not happen straight after treatment. They can develop slowly after treatment, over 2 to 5 years. Ask your cancer doctor about your risk of ED. There are different treatments that can help if you have ED.

## Bladder problems

Urine leaking from the bladder (urinary incontinence) can be a side effect of having HIFU treatment. This is more likely if you have already had external-beam radiotherapy (see pages 53 to 64). Most men have some incontinence when their catheter is first removed. This usually improves within a few months of having your operation.

Some men may still be incontinent when they cough, sneeze or exercise. This is called stress incontinence. Other men may have problems needing to pass urine straight away (urgency). You will be encouraged to do exercises to strengthen the pelvic floor muscles. You can do these at home. The Bladder and Bowel Community can give you more information on how to do these exercises (see page 131).

If you are having problems with incontinence, talk to your doctor or nurse. They can refer you to a continence team, who can give you advice about coping.

HIFU can cause narrowing in the urethra (urethral stricture). The urethra is the tube that runs from the bladder to the tip of the penis. It takes urine away from the bladder. If this happens, you may find it difficult to completely empty your bladder. If you are having problems passing urine, talk to your doctor or nurse.

### Rectal fistula

Rarely, HIFU can damage the structures surrounding the prostate and a hole develops between the rectum (back passage) and the urethra. This is called a rectal fistula. Talk to your doctor if you have:

- pain in your pelvis or back passage
- urine coming from your back passage
- poo (stools) in your urine.

If you have a rectal fistula, you will need an operation to repair it.

## Treatment before HIFU

Some men whose prostate gland is enlarged may have some other treatments before HIFU:

- Hormonal therapy (see pages 74 to 79). This can help to reduce the size of the prostate and make the cancer easier to treat.
- Transurethral resection of the prostate (TURP). This is a small operation that helps improve the flow of urine before you have HIFU. Improving the flow of urine means you may have fewer bladder problems after HIFU.

# Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy, or other treatment is better than what is already available.

## Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason.

However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

There is more detail in our booklet **Understanding cancer research trials (clinical trials)** – see page 126.

> 'The oncologist explained there was a trial going on and that I fitted the criteria. After it had been comprehensively explained to us, we were given paperwork to read. We then went back for another chat with a research nurse and finally agreed to go ahead with it.'
>
> **Andrew**

## Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

# AFTER TREATMENT

# Follow-up after treatment

After treatment has finished, you will have follow-up appointments.

If you have had surgery or radiotherapy, you will have regular check-ups after your treatment finishes. You will usually be seen at a clinic appointment every few months for the first year. After the first year, you will be seen every 6 months for up to 2 years. At the appointment, you will be asked about any side effects or new symptoms you are having. You will usually have a PSA test (see page 11) and a rectal examination.

If you are having ongoing hormonal treatment, you will continue to be checked at appointments, usually every few months.

You may see your cancer specialist for follow-up appointments, or you may have a PSA test at your GP surgery. You can talk to your cancer specialist about how you will have follow-ups after treatment. They can also tell you who you should contact if you have any problems in between appointments.

Many men find they get anxious before the appointments. This is natural. It may help to get support from family, friends or a support organisation (see pages 131 to 136). You can also call the Macmillan Support Line on **0808 808 00 00**.

## If prostate cancer comes back

After treatment, some men are cured of prostate cancer. But for others, cancer may come back after treatment. If your cancer comes back, you may be able to have further treatment.

What treatment you may be offered will depend on:

- the PSA level
- whether you have any symptoms
- whether you have already had treatment
- what type of treatment you have already had.

Your doctor can explain what treatment might be right for your situation.

# Well-being and recovery

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

Not everyone will have specific side effects, but they may have other, more general effects. These include:

- trouble sleeping or feeling more tired than usual
- losing or gaining weight
- stiff muscles or joints.

Having a healthy lifestyle can help your body recover. It may also help reduce the risk of other illnesses, such as heart disease and strokes.

> ‘I changed my lifestyle right at the start. As well as learning to eat the right foods and knowing what to avoid, I set myself a routine of exercising several times a week.’
>
> **Andy**

## Eat well and keep to a healthy weight

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

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

Our booklet **Healthy eating and cancer** has more information (see page 126).

## Limit alcohol

NHS guidelines suggest that men should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units they drink in a week over three or more days
- try to have several alcohol-free days every week.

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

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

## Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. Smoking increases your risk of bone thinning (osteoporosis) and is a major risk factor for smoking-related cancers and heart disease.

Our booklet **Giving up smoking** has practical advice about how to stop smoking and stay stopped (see page 126). There are also organisations that can help, such as Smokefree (see page 134).

## Keep active

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

Our booklet **Physical activity and cancer** has information about the benefits of being active and practical advice (see page 126).

## Look after your bones

Hormonal treatments for prostate cancer (see pages 74 to 79) can increase the risk of bone thinning (osteoporosis). Keeping physically active and eating a healthy diet with enough calcium and vitamin D helps keep your bones healthy. If you smoke, you should stop as this can also increase your risk of bone thinning.

> ‘For the first time ever, I was tired doing nothing. However, I walked my dog at least once a day for 15 to 20 minutes. The combination of mild exercise and fresh air started what became, for me, a fast recovery.’
>
> **Paul**

# Sex and relationships

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

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

We have included information about managing side effects in our information on individual treatments (see pages 40 to 89). As your side effects improve, you may feel more interested in having sex.

If cancer and its treatments affect your sex life, it can feel like a serious loss. You do not need to be in a relationship to feel this. But there are different ways to manage sexual difficulties.

Cancer and its treatments can also affect how you feel and think about your body (body image). You may feel less sexually attractive. If you are having issues with your body image, ask your doctor or nurse for advice. You may also find our booklet **Body image and cancer** helpful (see page 126).

Certain lifestyle changes may help improve body image concerns, such as being more physically active, eating healthily and managing your weight (see pages 94 to 97). Ask your doctor or nurse for advice.

You may find our booklet **Cancer and your sex life – information for men** helpful (see page 126).

## Sexual difficulties

Prostate cancer treatments can have a direct effect on your sex life. Some men may already have had sexual difficulties before their diagnosis. These are more common as men get older and are linked with conditions such as high blood pressure and raised cholesterol.

Different cancer treatments may:

- reduce your sex drive (libido)
- cause difficulties getting or keeping an erection (called erectile dysfunction, or ED)
- affect your ability to have an orgasm or to ejaculate.

If you are having sexual difficulties, there are different treatments and types of support to help you.

### Talking about sex

You may find it difficult to talk about sex with your doctor or nurse. But doctors and nurses who treat men with prostate cancer are used to talking about these issues. They can give you advice and answer your questions. If you need more specialist advice, they can refer you to an ED clinic or a sex therapist.

If you have questions about sex during or after treatment, ask your doctor or nurse. Having sex will not affect how well your treatment works. In some situations, they may advise you to be cautious about sex during treatment or immediately after it finishes.

For example, after surgery you may be advised to wait until your wound has healed. Side effects of pelvic radiotherapy, such as skin changes or tiredness, may make having sex difficult or you may not feel up to it. You may decide to wait until your side effects improve.

If you identify as gay, bisexual, transgender or LGBT+, you may worry about being treated insensitively by your healthcare team. Many sexual difficulties caused by prostate cancer are similar whatever your sexuality. But you may have some specific questions. Having your sexual or gender identity acknowledged may help you feel better supported. It also means your healthcare team can give you the right information and advice. Prostate Cancer UK has specific information for gay and bisexual men (see page 131).

If you feel unable to talk to your healthcare team about your sexuality, the LGBT Foundation has a helpline that can give you confidential advice and support (see page 136).

Pelvic radiotherapy and brachytherapy can affect the back passage (rectum). This can cause different side effects (see pages 59 to 62 and pages 70 to 71). If you receive anal sex, it is best to wait until these side effects have improved. It is important not to injure the tissues of the rectum. Radiotherapy may cause long-term changes to the rectum that may make receiving anal sex difficult. You can talk to your doctor or nurse for more advice. Prostate Cancer UK has specific information for gay and bisexual men (see page 131).

> ‘Being gay, I didn’t have the guts to talk to my doctor. I felt there was no one like me to talk to. But I’ve since had the opportunity to help others with my experiences.’
>
> **Simon**

## Managing sexual difficulties

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

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

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

### Erectile dysfunction (ED) recovery after treatment

Some men are offered an ED recovery package soon after treatment. This is usually called penile rehabilitation. You regularly use one or more treatments, such as tablets or a pump, to encourage blood-flow to the penis after surgery (see pages 44 to 52) or radiotherapy (see pages 53 to 73). This is to help the penis recover – it is not just for sex. When you are ready to start having sex, you should have a better chance of getting an erection. Your doctor or nurse can tell you more about this.

> ‘Because of my operation, I am no longer able to get an erection naturally. I chose to take that risk after discussing it with my wife. I use either injections or a machine to get an erection.’
>
> **Neil**

### Tablets

This is the most common treatment for ED. You take the tablets before you have sex. There are different ones you can try. Some may work better than others for you. You need to have sexual stimulation to get an erection. If you have heart problems, these may not be recommended for you. They should not be taken with certain drugs.

- **Sildenafil (Viagra®)** increases the blood supply to the penis. You take it about 60 minutes before sex. It should be prescribed by your GP. Side effects include heartburn, headaches, dizziness and changes in eyesight, such as a blue tint to your vision.
- **Vardenafil (Levitra®)** is similar to sildenafil and works within an hour. Common side effects are headaches and facial flushing.
- **Tadalafil (Cialis®)** helps increase blood flow to the penis during sexual arousal. You take it either up to 2 hours before sex or every day.
- **Avanafil (Spedra®)** is taken about 30 minutes before sex. Side effects include headaches, nasal congestion and back pain.

### Injections

These may work better than tablets for men who have ED due to nerve damage. You use a small needle to inject a drug called alprostadil (MUSE®) directly into the shaft of the penis. The drug restricts blood flow out of the penis. This causes an erection in 5 to 20 minutes. A healthcare professional will give you the first dose and teach you how to do this yourself. You start with a low dose of the injection, which you can increase to find the right dose for you.

### Pellets or creams

You can get alprostadil (MUSE®) as pellets or as cream (Vitaros®). You insert it into the opening of the penis with an applicator. This should not be uncomfortable. The cream or pellet is absorbed into the penis and produces an erection. The drug may cause a burning feeling in the urethra or pain in the penis. You have the first dose in hospital and it can be adjusted until you find the right dose.

### Pumps

Vacuum pumps can be used to produce an erection. They may be called vacuum erection devices (VEDs). The pump is a hollow tube that you put your penis into. It makes the penis fill with blood by creating a vacuum. You put a stretchy ring around the base of the penis to hold the erection. It can be maintained for up to 30 minutes.

### Implants

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

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

# Infertility

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

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

We have more information in our booklet **Cancer treatment and fertility – information for men** – see page 126.

# Relationships

## If you have a partner

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

There are different ways you can show your partner you care about them. This can include spending time together and showing affection through touching, holding hands or putting an arm around their shoulder. 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. There is more information about this in our booklet **Cancer, you and your partner** (see page 126).

> ‘My partner came with me to appointments, so there were no assumptions about my sexuality. This took a great deal of pressure off me.’
>
> **Simon**

## 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 has a list of nationwide counsellors and therapists who can offer advice and support – visit **cosrt.org.uk**

# YOUR FEELINGS AND RELATIONSHIPS

---

# Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

## Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

## Fear and anxiety

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

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

## Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

## Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

## Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups** You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

## If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them. See page 126 for details of how to order it.

# What you can do

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

## Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you've dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a more healthy diet, by getting fitter or by finding a relaxing complementary therapy. You might find it helpful to read our booklets **Healthy eating and cancer**, **Physical activity and cancer** and **Complementary therapies and cancer** (see page 126).

Understanding about the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.

# If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit **macmillan.org.uk/learnzone** to find out more.

Our booklet **Talking to someone who has cancer** has more suggestions if you have a friend or relative with cancer. If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information. See page 126 for details of how to order our booklets.

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**

# Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

## Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.


LV53 WTU
0A

# FINANCIAL SUPPORT AND WORK

# Financial help and benefits

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

## Statutory Sick Pay

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

## Benefits

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

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

### Employment and Support Allowance (ESA)

This benefit is for people under state pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

### Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

### Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

### Special rules

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

## Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

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

## Macmillan Grants

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

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

How much you get will depend on your situation and needs. The average grant is around £400. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

## Insurance

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

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** – see page 126.

Our Online Community forum **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

## More information

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

You can also get information about benefits and other types of financial help from **Citizens Advice** (see page 136).

Our booklet **Help with the cost of cancer** has lots more information (see page 126).

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

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

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

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful – see page 126. There is also lots more information at **macmillan.org.uk/work**

## Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

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

Our booklet **Your rights at work when you are affected by cancer** has more information – see page 126.


BE.MACMILLAN
WANT TO MAKE OR ORDER SOMETHING?

# FURTHER INFORMATION

---

# About our information

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

## Order what you need

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

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

## Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

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

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

Find out more at **macmillan.org.uk/otherformats**
If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.

# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:

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

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

### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

## Talk to others

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

### Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand.

Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

### Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things.

You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

## The Macmillan healthcare team

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

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

## Help with work and cancer

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

## My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

## There are lots of other organisations that can give you information or support.

### Prostate cancer support organisations

**Bladder and Bowel Community**
**Tel** 0800 031 5412
**Email**
help@bladderandbowel.org
**www.bladderandbowel.org**
Provides information and advice on a range of symptoms and conditions related to the bladder and bowel, including incontinence, constipation and diverticular disease.

**Orchid**
**Tel** 0808 802 0010
**Email**
helpline@orchid-cancer.org.uk
**www.orchid-cancer.org.uk**
Funds research into men's cancers and their diagnosis, prevention and treatment. Offers free information leaflets and fact sheets, and runs an enquiry service supported by Orchid male cancer information nurses.

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

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

### Tackle Prostate Cancer (Prostate Cancer Support Federation)

**Tel** 0800 035 5302
**Email**
helpline@tackleprostate.org
**www.tackleprostate.org**
An organisation made up of UK patient-led prostate cancer support groups.

## Support with sexual issues

### The Sexual Advice Association

**www.sda.uk.net**
Aims to improve the sexual health and well-being of men and women, and to raise awareness of how sexual conditions affect the general population.

## General cancer support organisations

### Cancer Black Care

**Tel** 020 8961 4151
**www.cancerblackcare.org.uk**
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

### Cancer Focus Northern Ireland

**Helpline** 0800 783 3339
(Mon to Fri, 9am to 1pm)
**Email**
nurseline@cancerfocusni.org
**www.cancerfocusni.org**
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

### Cancer Research UK

**Helpline** 0808 800 4040
(Mon to Fri, 9am to 5pm)
**www.cancerresearchuk.org**
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### Cancer Support Scotland

**Tel** 0800 652 4531
(Mon to Fri, 9am to 5pm)
**Email**
info@cancersupportscotland.org
**www.cancersupportscotland.org**
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### Macmillan Cancer Voices

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

### Maggie's Centres

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

### Penny Brohn UK

**Helpline** 0303 3000 118
(Mon to Fri, 9.30am to 5pm)
**Email**
helpline@pennybrohn.org.uk
**www.pennybrohn.org.uk**
Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

### Riprap

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

### Tenovus

**Helpline** 0808 808 1010
(Daily, 8am to 8pm)
**Email**
info@tenovuscancercare.org.uk
**www.tenovuscancercare.org.uk**
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

## General health information

### Health and Social Care in Northern Ireland

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

### Healthtalk

**Email** info@healthtalk.org
**www.healthtalk.org**
**www.healthtalk.org/young-peoples-experiences** (site for young people)
Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

### NHS.UK

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

### NHS Direct Wales

**www.nhsdirect.wales.nhs.uk**
NHS health information site for Wales.

### NHS Inform

**Helpline** 0800 22 44 88
(Mon to Fri, 8am to 10pm, Sat and Sun 9am to 5pm)
**www.nhsinform.scot**
NHS health information site for Scotland.

### NHS Smokefree

**Helpline** 0300 123 1044
(Mon to Fri, 9am to 8pm, Sat and Sun, 11am to 4pm)
**www.nhs.uk/smokefree**
Offers information and advice for people who want to stop smoking, including information on local stop smoking services in England.

### Patient UK

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

## Counselling

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

**Tel** 01455 883 300
**Email** bacp@bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

### UK Council for Psychotherapy (UKCP)

**Tel** 020 7014 9955
**Email** info@ukcp.org.uk
**www.psychotherapy.org.uk**
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## Emotional and mental health support

### Mind

**Helpline** 0300 123 3393
(Mon to Fri, 9am to 6pm)
**Text** 86463
**Email** info@mind.org.uk
**www.mind.org.uk**
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

### Samaritans

**Helpline** 116 123
**Email** jo@samaritans.org
**www.samaritans.org**
Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## Financial or legal advice and information

### Benefit Enquiry Line Northern Ireland

**Helpline** 0800 022 2450
(Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
**Textphone** 028 9031 1092
**www.nidirect.gov.uk/money-tax-and-benefits**
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### Citizens Advice

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

### England

**Helpline** 03444 111 444
**www.citizensadvice.org.uk**

### Scotland

**Helpline** 0808 800 9060
**www.citizensadvice.org.uk/scotland**

### Wales

**Helpline** 03444 77 2020
**www.citizensadvice.org.uk/wales**

### Northern Ireland

**Helpline**
028 9023 1120
**www.citizensadvice.co.uk**

## LGBT-specific support

### LGBT Foundation

**Tel** 0345 330 3030
(Mon to Fri, 10am to 10pm, Sat, 10am to 6pm)
**Email** helpline@lgbt.foundation
**www.lgbt.foundation**
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

## 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 our Senior Medical Editors, Dr Jim Barber, Consultant Clinical Oncologist and Dr Lisa Pickering, Consultant Medical Oncologist.

With thanks to: Dr Alison Birtle, Consultant Clinical Oncologist; Jane Booker, Macmillan Urology Nurse Specialist; Mr Christian Brown, Consultant Urological Surgeon; Sharon Clovis, Prostate Nurse Specialist; Gill Davis, Specialist Urology Nurse; Louise Dawson, Macmillan Uro-oncology Clinical Nurse Specialist; Ben Hearnden, Prostate Nurse Specialist; Mr Graham Hollins, Consultant Urological Surgeon; Dr Duncan McLaren, Consultant Clinical Oncologist; and Professor Jonathan Waxman, Professor of Oncology.

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

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

# Sources

We've listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

European Association of Urologists. Guidelines on prostate cancer. 2016.
European Society for Medical Oncology. Cancer of the prostate: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. 2015.
National Institute for Health and Care Excellence (NICE). Prostate cancer overview. https://pathways.nice.org.uk/pathways/prostate-cancer (accessed from March 2017 to November 2017).
National Institute for Health and Care Excellence (NICE). Surveillance report 2016. Prostate cancer: diagnosis and management (2014). NICE guideline CG175. 2016.

# Can you do something to help?

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

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

5 WAYS
YOU CAN
HELP
SOMEONE
WITH
CANCER

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

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

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

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

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

## Call us to find out more

**0300 1000 200**

**macmillan.org.uk/getinvolved**

## Please fill in your personal details

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 / /

## Don’t 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.**

Registered with FUNDRAISING REGULATOR

**If you’d rather donate online go to macmillan.org.uk/donate**

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

**27530**

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

**The booklet explains the signs and symptoms of early prostate cancer. It explains how it is diagnosed and how it can be treated. It also has information about emotional, practical and financial issues.**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

© Macmillan Cancer Support, May 2018. 5th edition. MAC11639_E05_N. Next planned review 2020. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Printed using sustainable material. Please recycle.