MACMILLAN
CANCER SUPPORT

UNDERSTANDING ADVANCED (METASTATIC) PROSTATE CANCER

> During treatment, I was told about a Macmillan centre in the hospital. At a time when I was coming to terms with everything, it was a haven for me.

Alan, diagnosed with advanced prostate cancer

About this booklet

This booklet is for anyone who has been diagnosed with advanced (metastatic) prostate cancer. This is when prostate cancer has spread to other parts of the body, such as the bones. There is also information for carers, family members and friends.

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

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 don’t 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 127 to 132).

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 experiences with us by becoming Cancer Voices. This includes Alan, who is on the cover of this booklet.

To share your experience, visit **macmillan.org.uk/shareyourstory**

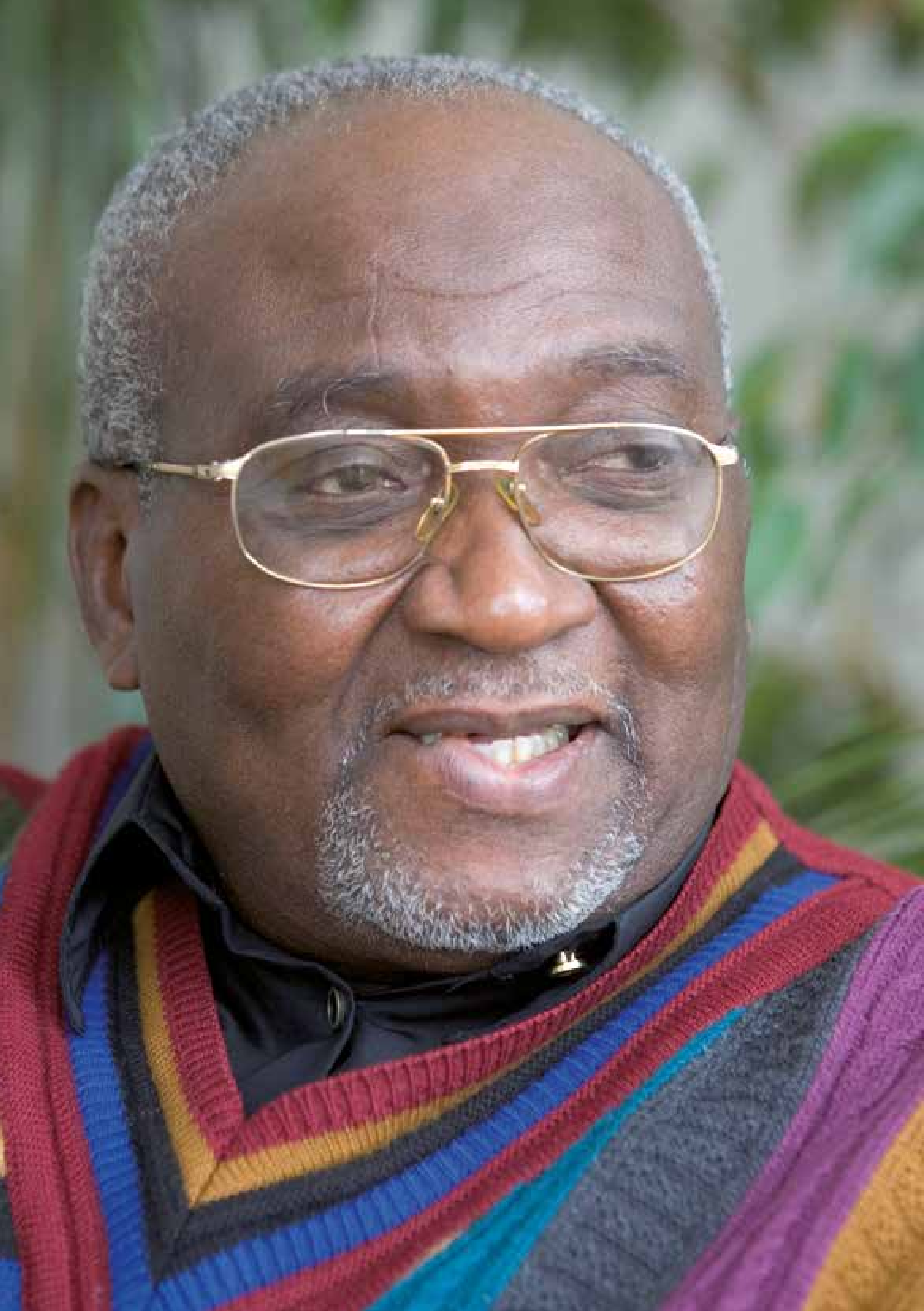
For more information

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.

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

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use. If you are deaf or hard of hearing, call us using 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

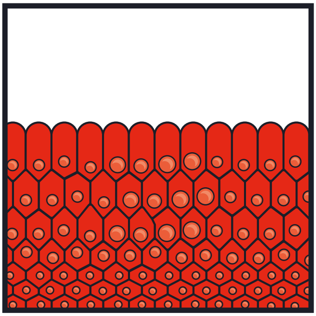
THE PROSTATE AND PROSTATE CANCER

What is cancer?

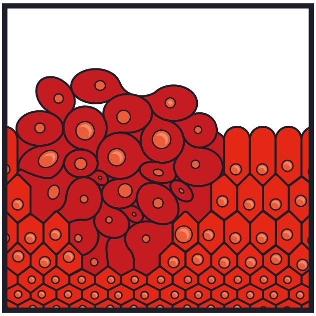
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop 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.

Normal cells



Cells forming a tumour



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.

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 (see pages 14 to 15). 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.

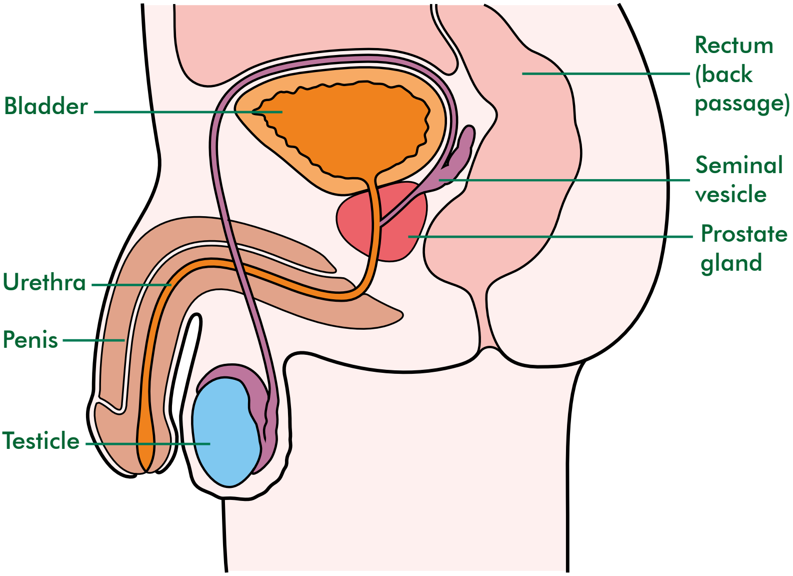
The prostate

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 pages 14 to 15.

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

The 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 (see page 29). Doctors use it to help diagnose different prostate problems, including cancer.

Advanced 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.

Advanced prostate cancer is when the cancer cells have spread to other parts of the body. It is not possible to cure advanced prostate cancer. But there are treatments that can help to keep it under control (see pages 39 to 81).

The most common place for prostate cancer to spread to is the bones. It may also spread to lymph nodes outside the pelvis, or rarely to the liver or the lungs.

Advanced prostate cancer may develop in men who have previously been treated for prostate cancer. This may be many years later. In some men, prostate cancer has already spread to other parts of the body when it is first diagnosed.

The cancer cells usually spread through the blood or through the lymphatic system (see pages 14 to 15). When the cancer cells reach a new area of the body, they go on dividing and form another cancer. This is called a secondary cancer or metastasis. But it is still prostate cancer.

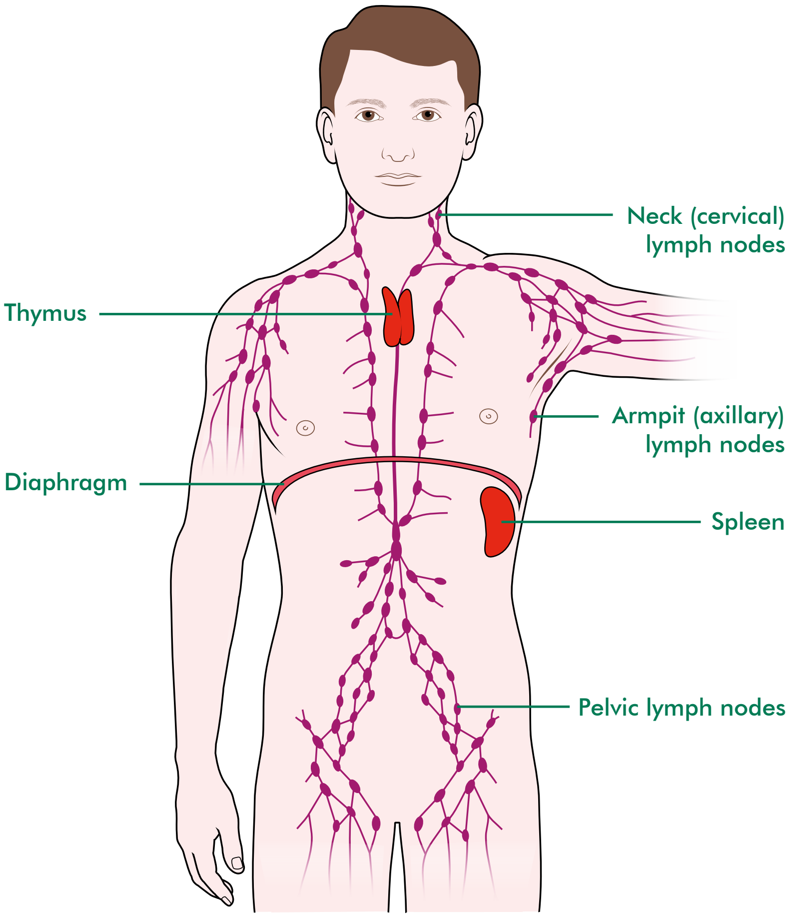
The lymphatic system

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.

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

The lymphatic system



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 provide 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. See page 127 for Prostate Cancer UK's contact details.

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).

Talk to your GP if you have a family history of cancer and are concerned about your prostate cancer risk.

Our booklet **Cancer genetics – how cancer sometimes runs in families** has more information. See page 122 for ways to order this.

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.

We have more information in our booklets **Healthy eating and cancer** and **Physical activity and cancer treatment.** See page 122 for ways to order these booklets.

Symptoms of advanced prostate cancer

Prostate cancer often grows slowly. Symptoms may not develop for many years. The symptoms of advanced prostate cancer may be due to an enlarged prostate.

Symptoms of an enlarged prostate can include:

- difficulty peeing – for example, a weak flow or having to strain to start peeing
- needing to pee more often than usual, especially at night
- feeling like you have not completely emptied your bladder after peeing
- blood in the pee or semen
- rarely, pain when peeing or ejaculating.

You may also have symptoms if the cancer has spread to another part of the body (secondary cancer). The symptoms will depend on which part of the body is affected. But the most common place for prostate cancer to spread to is the bones.

Some men have a few general symptoms which may include:

- being more tired than usual
- generally feeling unwell
- having less of an appetite.

If you have any of the symptoms we mention here, it is important to have them checked by your doctor.

> ‘Just like other people, I thought my symptoms were part of old age. But a friend of mine said, “Go to your GP and get tested”, so I did.’
>
> **Desmond**

Secondary cancer in the bones

Prostate cancer may spread to bones such as the spine, pelvis, thigh bone (femur) or ribs. It may affect different areas of the bones rather than only one area.

Pain

The first sign of a secondary cancer in the bones is usually an ache in the bone. This is often in the hips or in the back. The pain gradually gets worse over a few weeks. You may have pain during the day but also at night, making it difficult to sleep.

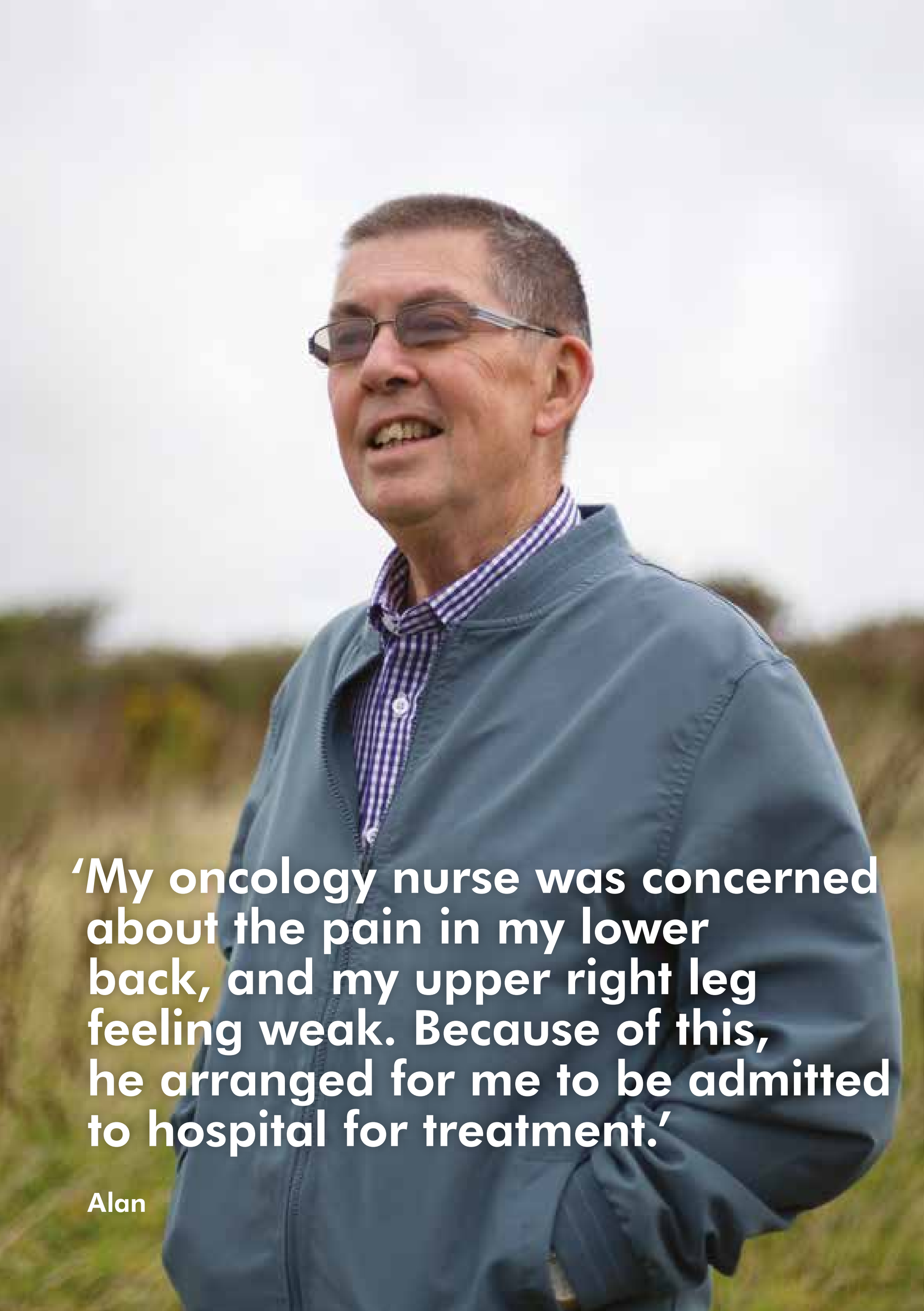
You usually need to take painkillers to help you. Other types of pain not caused by cancer may feel different. For example, pain from arthritis is often worse early in the morning and is not there all the time.

A secondary cancer in the bone may gradually make the bone weaker. Pain and weakness can make getting around difficult. Bones that are very weak may break (fracture) more easily. There are treatments you can have to help strengthen the bones and reduce pain.

We have more information in our booklets:

- **Understanding secondary cancer in the bone**
- **Managing cancer pain**
- **Managing the symptoms of cancer**.

See page 122 for ways to order these booklets.



> ‘My oncology nurse was concerned about the pain in my lower back, and my upper right leg feeling weak. Because of this, he arranged for me to be admitted to hospital for treatment.’
>
> **Alan**

Spinal cord compression

If the bones in the spine have cancer in them, the cancer may press on the spinal cord. This is called spinal cord compression.

It usually affects your legs and may cause:

- pain
- weakness
- numbness or tingling in your legs.

Spinal cord compression is not common. But if you notice these symptoms, you should contact your doctors straight away – even at the weekend or during a holiday period. If you cannot contact your GP or cancer doctor, you should go to the nearest emergency department (A&E).

We have more information about spinal cord compression that we can send you. Call us on **0808 808 00 00** (7 days a week, 8am to 8pm).

Anaemia

Prostate cancer can sometimes spread from the bone into the bone marrow. Bone marrow is the spongy material in the centre of our bones where our blood cells are made. This includes red blood cells, which carry oxygen around the body.

If the bone marrow cannot produce enough red blood cells, you may become anaemic. This can make you feel very tired and breathless, and you may look very pale.

Other symptoms

Prostate cancer can sometimes spread to other parts of the body, such as the lymph nodes, lungs or liver. If you notice any new symptoms that last for 2 weeks or more, you should talk to your cancer specialist.

It is important to remember that any of the symptoms mentioned here can be caused by problems other than cancer.

DIAGNOSING ADVANCED PROSTATE CANCER

How advanced prostate cancer is diagnosed

How you are diagnosed with advanced prostate cancer will depend on your situation. It may be:

- after previous treatment for early or locally advanced prostate cancer – possibly many years ago
- after being diagnosed with cancer in the prostate, if further tests show the cancer is advanced
- after tests to check symptoms of bone pain, with no previous diagnosis of prostate cancer.

The most common places for prostate cancer to spread to is the bones and lymph nodes outside the pelvis (see pages 14 to 15). It rarely spreads to areas such as the lungs or liver.

Tests

Your doctor or specialist nurse will explain the tests that are best for your situation. You may not need all the tests we mention here. If you have had prostate cancer before and have symptoms, you will have tests to see if the cancer has spread. These usually include a PSA test and bone scan.

If you have just been diagnosed with prostate cancer, you will have further tests to see if the cancer is advanced. These include a bone scan, CT scan or MRI scan.

If you were diagnosed with secondary cancer in the bones, you will need tests to find out if it started in the prostate. These include a PSA test.

PSA test

Your doctors will take a blood sample to check the level of PSA (prostate-specific antigen) in your blood. PSA is a protein produced by the prostate. There is normally a small amount of PSA in the blood. Men with prostate cancer tend to have a raised level of PSA. But the test is not always reliable.

PSA levels get higher as men get older. Different things can raise PSA levels. But most men with advanced prostate cancer will have a very high PSA level.

If you have had prostate cancer before, you will have had regular blood tests to check your PSA levels.

Biopsy

Depending on your situation, you may be offered a biopsy of the prostate. This is when several small samples of tissue (usually around 10 to 12) are taken from the prostate and examined under a microscope for cancer cells.

If you have a very high PSA or scans show the cancer has spread, you may not need a biopsy.

Some men have a biopsy from the area of the secondary cancer. This is to find out if it is a cancer and what type it is. This is only usually if you have not been diagnosed with prostate cancer before.

X-rays

You may have x-rays of the bones in a painful area to find out if there are any abnormal areas.

Bone scan

This test can usually tell if the cancer has spread to the bones. The person doing the scan gives you a radioactive substance as an injection into a vein. After you have the injection, you will need to wait 2 to 3 hours before you have the scan. The person will then use a special camera to take a scan of your bones.

MRI (magnetic resonance imaging) scan

This scan uses magnetism to build up a detailed picture of areas of the body. You may have an injection of dye into a vein to improve the images from the scan. It can be used to look at the prostate and different parts of the body to see if the cancer has spread.

Some men may have an MRI scan before they have a biopsy. Specialised scans called multi-parametric MRI scans can give doctors more detailed images of the body. These images give more information about a suspected area of cancer. Depending on the results of the scan, your doctor may explain that you do not need a biopsy.

CT (computerised tomography) scan

A CT scan takes a series of x-rays which build up a three-dimensional picture of the inside of the body.

We have more information about tests and scans on our website – visit **macmillan.org.uk/testsandscans**

Waiting for your test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. Your doctor will tell you the results and talk to you about the best treatment for your situation. Most prostate cancers grow very slowly. Even if it takes a couple of weeks to get your results, it is unlikely that the cancer will change during this time.

People have different support networks. Whether yours is your family, your partner, a friend or a social group, try to talk to someone you trust about how you are feeling.

If you feel you have no one to talk to, you can call our cancer support specialists on **0808 808 00 00**, or visit our Online Community (**community.macmillan.org.uk**) where you can speak to other people who understand. There are lots of other sources of support too (see pages 127 to 132).

> ‘My husband was recently diagnosed with advanced prostate cancer. Waiting for results can be horrible. But the people in Macmillan’s Online Community are wonderful. I have had so much help from the prostate cancer group.’
>
> **Carole**

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.

Your doctors also look at the grade of the cancer to help them plan your treatment (see page 36).

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

T N M 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 for metastasis.

T Tumour

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

- T1 and T2 tumours are known as early (localised) prostate cancer. They are contained in the prostate.
- T3 tumours have spread outside the prostate and may be growing into tissues or organs close by.
- T4 tumours have spread into areas close by, such as the bladder or back passage (rectum), or the muscle that controls peeing.

N Nodes

- N0 means there is no cancer in the lymph nodes near the prostate.
- N1 means there is cancer in 1 or more lymph nodes close by.

M Metastasis

M1 means the cancer has spread to another part of the body, so advanced prostate cancer is always M1.

With the TNM staging system, advanced or metastatic prostate cancer can be any T, any N, and always M1.

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. Advanced or metastatic prostate cancer is always stage 4. But some stage 4 cancers are locally advanced.

Our booklet **Understanding locally advanced prostate cancer** has more information – see page 122 for ways to order this.

Stage 4 can be either of the following:

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

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).

Most men with advanced prostate cancer have a high Gleason grade.

Your data and the cancer registry

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

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

Treatment overview

When prostate cancer has spread to other parts of the body, such as the bones, you can have treatments to help to control the cancer. Although the cancer cannot be cured, it can be controlled, sometimes for several years. Treatments can also help relieve symptoms and improve your quality of life.

Your doctor and nurse will help you to understand the treatments and how they may affect you. If you have someone close to you, it can help to take them to appointments with your healthcare team. They may remember any questions you have or information you have been given.

> ‘I did not think I would be here now. It was only after having my diagnosis, when I began to read more about the disease, that I discovered it can be controlled for quite some time. It is still under control 15 months later.’
>
> **Charlie**

Treatments

The main treatments are hormonal therapy, chemotherapy and radiotherapy. Some men have a combination of these. Your cancer doctor and nurse will talk to you about the treatments that may be helpful in your situation. This will depend on:

- your general health
- where the cancer is and the symptoms it is causing
- any previous treatments you have had for prostate cancer
- how treatments and their side effects will affect your everyday life.

Your doctor will consider your preferences and help you decide on the right treatment plan for you.

Hormonal therapy

Prostate cancer needs testosterone to grow. Hormonal therapies reduce the amount of testosterone in the body. This may slow the growth of the cancer or stop it growing for a while.

Hormonal therapy is recommended for most men with advanced prostate cancer. You can have it as injections. You often have these injections alongside hormonal tablets. Some men have hormonal therapy along with chemotherapy.

There is more information about hormonal therapies on pages 49 to 59.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Some men have it with hormonal therapy when they are first diagnosed with advanced prostate cancer. Or it may be given when hormonal therapy is no longer controlling the cancer.

There is more information about chemotherapy on pages 60 to 66.

Radiotherapy

You may have radiotherapy to improve symptoms such as pain in the prostate area or the bones. Radiotherapy can also help strengthen a weakened bone.

There is more information about radiotherapy on pages 68 to 73.

Surgery

Surgery to remove the prostate is not suitable for men with advanced prostate cancer. Some men may have an operation called a transurethral resection of the prostate (TURP) to help relieve problems with passing urine (peeing).

Another type of operation removes part of the testicles. This is called a subcapsular orchidectomy. It is done to reduce the amount of testosterone in the body.

Surgery may also be used to help control other symptoms or to help stabilise a bone that is at risk of breaking.

There is more information about surgery on pages 74 to 79.

There are other treatments available that can relieve and control any symptoms you may have (see pages 84 to 93).

We have a video on our website about treating advanced prostate cancer. You can view it at **macmillan.org.uk/treatmentforadvancedprostatecancer**

Specialist nurses called palliative care nurses can also provide help and support. They are experienced in assessing and treating symptoms of advanced cancer. You may meet them when you are at a clinic or in hospital.

There is also support available to help you cope with the emotional impact of cancer and its treatment. Your cancer doctor or GP may be able to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about support services and counselling in your area.

How your treatment is planned

If you have just been diagnosed with prostate cancer, a team of specialists will meet to discuss the best possible treatment for you. This multidisciplinary team (MDT) will include:

- an oncologist (cancer doctor)
- a surgeon
- a specialist nurse who gives information and support.

It may also include other healthcare professionals, such as:

- a doctor who specialises in symptom control (palliative care doctor)
- a dietitian
- a physiotherapist
- an occupational therapist (OT)
- a psychologist or counsellor.

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 specialist nurse discussed the diagnosis and treatment plan options with me. It was very informative and he provided me with lots of leaflets I could read.’
>
> **Alan**

Advantages and disadvantages of treatments

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

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

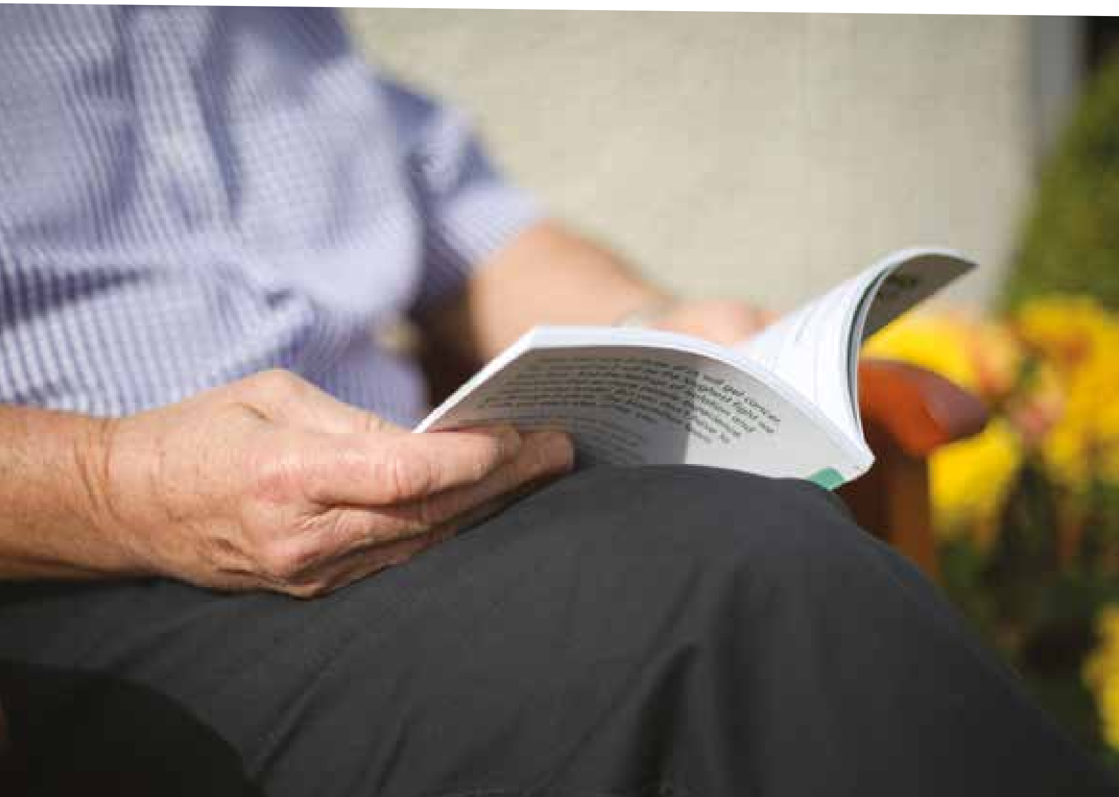
Making decisions in these circumstances is always difficult. You may want to talk it over carefully with your cancer doctor, specialist nurse and family. It may also help to discuss the options with our cancer support specialists on **0808 808 00 00**.

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

Making treatment decisions

There are often decisions to be made about which treatment to have, or whether to have treatment. You can take as large or small a part in making decisions as you wish. Your healthcare team can help you make the right decision for you.

Our booklet **Making treatment decisions** has more information – see page 122 for ways to order this.



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 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.

Hormonal therapy

Hormonal therapy is the main treatment for men with advanced prostate cancer. It can shrink the cancer, slow its growth and reduce symptoms.

Your doctor or nurse will talk to you about the type of hormonal therapy that is best for your situation. They will explain the different side effects (see pages 57 to 59) and talk to you about your preferences.

Prostate cancer needs the hormone testosterone to grow. Testosterone is mainly made by the testicles. A small amount is made by the adrenal glands, above each kidney.

Hormonal therapies lower your testosterone levels or stop it reaching the cancer cells.

Testosterone is important for:

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

Your doctor or nurse will check how well your hormonal therapy is working. They will ask about your symptoms, examine you and monitor your PSA level (see page 29). PSA is usually a good guide to how well treatment is working. If it goes up, they may talk to you about having a different hormonal therapy.

How you have hormonal therapy

There are different types of hormonal therapy. You can have them as:

- injections
- implants
- a nasal spray
- tablets.

You might have a drug on its own or along with another hormonal therapy.

Another way of reducing testosterone is to have an operation called an orchidectomy to remove the testicles (see page 52). This is not commonly done.

Some men have hormonal therapy with chemotherapy when they are first diagnosed with advanced prostate cancer (see pages 60 to 66). This may be more effective than hormonal therapy on its own. But there are more side effects to cope with. Your cancer doctor can tell you more about this.

Intermittent hormonal therapy

Instead of taking the drugs continuously, you may stop taking the drugs for a while and then start taking them again. This is called intermittent hormonal therapy. It means you get a break from the side effects of hormonal therapy. This is not suitable for everyone. It should only be done following your doctor's advice.

Intermittent hormonal therapy may be helpful in some men when certain side effects are difficult to cope with. Your doctor or nurse will explain the possible advantages and disadvantages. If your PSA level begins to rise or your symptoms get worse, your doctor will advise starting hormonal therapy again.

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. You may have treatment which involves having more than one type of therapy at a time.

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. These are often the first drugs used. You have them as an implant injection or an injection under the skin.

The commonly used LHRH agonists are:

- buserelin (Suprefact®)
- 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.

- Buserelin is given as an injection under the skin 3 times a day for a week. After this you take it as a nasal spray 6 times a day.
- 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 (see opposite page). You take it for a short time before and after starting the LHRH agonist.

We explain more about side effects on pages 57 to 59. We also have information about the drugs used in hormonal therapies on our website – visit **macmillan.org.uk**

GnRH antagonists

These drugs block messages from the brain to the testicles telling them to make testosterone. They work more quickly than LHRH agonists and do not cause tumour flare. At the moment degarelix (Firmagon®) is the only GnRH antagonist available. You have it as an injection under the skin (subcutaneously) of your tummy once a month. It may be used for advanced prostate cancer that has spread to the spine (back). As well as hormonal side effects, it commonly causes skin reactions.

Surgery to the testicles

Occasionally, men have an operation to remove part or all of the testicles. This is called an orchidectomy. It is not commonly done. It is more common to use hormonal therapy drugs to lower testosterone. But it may be an option if you find it hard to have regular injections or to take tablets every day. It is as effective as other hormonal treatments. You can have the operation as a day patient.

The operation cannot be reversed, which may be upsetting. It causes most of the same side effects you get with other hormonal therapy drugs. It is important to talk it over carefully with your doctor and nurse.

Combined hormonal therapy

If the cancer starts growing during treatment with an injection or implant, your doctor may advise taking an anti-androgen tablet as well.

Having the two drugs together can help to slow the cancer from growing or spreading. You will not usually have combined hormonal therapy as your first treatment. This is because you may have more side effects if you are taking two drugs. Your doctor or specialist nurse can explain more about this.

Some men may have newer hormonal therapy drugs called abiraterone (Zytiga®) or enzalutamide (Xtandi®) along with an injection or implant – see pages 55 to 56.

Anti-androgen drugs

These drugs block testosterone from reaching the cancer cells. You take them as tablets. They may be given:

- for 1 or 2 weeks before and after starting injections or implants, to stop symptoms getting temporarily worse (tumour flare)
- on their own
- with hormonal injections or implants (combined hormonal therapy).

An anti-androgen on its own may cause fewer sexual side effects (see page 57). But it may not be as effective in controlling the cancer as other hormonal therapies.

Anti-androgen drugs include:

- bicalutamide (Casodex®)
- cyproterone acetate (Cyprostat®)
- enzalutamide (a newer type of anti-androgen drug)
- flutamide.

Bicalutamide and flutamide can cause breast swelling or tenderness. As well as hormonal side effects, these drugs have different side effects of their own.

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

We have more information about these drugs on our website – visit **macmillan.org.uk**

> ‘I have been told that I will not be cured, and will remain on hormonal therapy for the rest of my life. At some stage, the PSA will start to go up again, and at that time I will need my treatment to be looked at again. However, right now I feel fine.’
>
> **Alan**

Newer hormonal therapy drugs

These drugs are usually used when other hormonal therapies are no longer helping to control the cancer. This is when the prostate cancer cells need much lower levels of testosterone to grow. Sometimes you may have these drugs earlier on, when you are first diagnosed.

Newer hormonal therapy drugs include:

- abiraterone
- enzalutamide.

These newer hormonal therapy drugs may be given before you need chemotherapy. This is if you have no symptoms or mild symptoms, or if chemotherapy is no longer helping to control the cancer. Or they may sometimes be given as the first hormonal therapy you have. This may be with hormonal injections or implants, or on their own.

Abiraterone

You take abiraterone as tablets once a day along with drugs called steroids.

If you have already had enzalutamide, you may not always be able to have abiraterone. Side effects of abiraterone can include high blood pressure and changes to your heartbeat. Your doctor or specialist nurse can give you more information.

Adding abiraterone to standard hormonal therapy as a first hormonal treatment may help men with advanced prostate cancer to live for longer. But this is not standard treatment.

Doctors still need to know if the benefits outweigh the side effects of this combined treatment. However, trial results are promising and the NHS is looking at how effective this is for the cost involved. Your doctor can talk to you about the benefits and disadvantages of this treatment in your situation.

Enzalutamide

You take enzalutamide as a capsule once a day. If you have already had abiraterone, you may not always be able to have enzalutamide. Side effects can include high blood pressure and, less commonly, an increased risk of infection. Your doctor or specialist nurse can give you more information.

Other hormonal treatments

Steroids

Sometimes steroid drugs such as prednisolone or dexamethasone are used to treat advanced prostate cancer. They work on the adrenal glands, to help reduce testosterone.

They are occasionally used on their own or given along with abiraterone. You may have dexamethasone along with a hormonal injection or implant drug. Side effects may include increased appetite, weight gain, difficulty sleeping and irritability.

Oestrogen

Treatment with the hormone oestrogen may help to reduce testosterone levels. It is occasionally used when other hormonal therapies are no longer working. The most commonly used drug is diethylstilbestrol (Stilboestrol®). You take it as a tablet.

The side effects are similar to other hormonal therapies. It can also increase the risk of getting a blood clot, so it may not be suitable for some men.

Side effects

Hormonal therapies all have similar side effects because they lower the level of testosterone. But individual drugs do have different side effects. It is important to discuss these with your doctor or nurse before you start treatment so that you know what to expect.

Erection difficulties

Most hormonal therapies cause loss of sexual desire and erection difficulties (called erectile dysfunction, or ED) – see pages 94 to 98.

LHRH agonists usually completely stop erections during treatment. Anti-androgens stop erections in most but not all men. If you have ED, there are drugs and treatments that may help. Your doctor or nurse will talk to you about this.

Hot flushes and sweats

These may happen less often as your body adjusts to treatment. Wearing layers of light clothing (preferably cotton) you can easily take off or put back on can help. Cutting down on alcohol, nicotine and hot drinks that contain caffeine can also help. If your hot flushes are causing you difficultly, your doctor may prescribe a drug to help reduce them.

Tiredness

Tiredness is a common side effect. It can be made worse by hot flushes, which may make sleeping difficult. Pace yourself so you have more energy to do the things you want. Regular physical activity, such as walking, can help give you more energy. Ask your team for advice on the type of exercise that is suitable for your situation. If tiredness makes you feel sleepy, do not drive or operate machinery.

Our booklet **Coping with fatigue** has more information – see page 122 for ways to order this.

Breast swelling or tenderness

Certain drugs (most commonly flutamide and bicalutamide) may cause breast swelling and breast tenderness. You may have 1 or 2 treatments with low-dose radiotherapy to the breast tissue to prevent swelling. Or you may have a tablet called tamoxifen to reduce swelling.

Weight gain and loss of muscle strength

It is common to put on weight (often around the tummy) with hormonal therapy. Try to eat a healthy, balanced diet. Regular physical activity, such as short walks, can help keep your weight stable and look after your muscles.

Resistance exercises, such as lifting weights, may help you to reduce loss of muscle strength. Ask your doctor or nurse for advice.

We have more information in our booklets **Healthy eating and cancer** and **Physical activity and cancer treatment**. See page 122 for ways to order these booklets.

Bone thinning

Hormonal therapy can cause bone thinning (osteoporosis). This can sometimes lead to tiny cracks in the bone (fractures). The risk increases if you are taking hormonal therapy for long periods.

If you are starting long-term hormonal treatment, your doctors may arrange for you to have a DEXA (dual-energy x-ray absorptiometry) scan. This allows them to check your bones for any areas of weakness or fractures.

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

If your bones are thinning, your doctor may advise you to take calcium and vitamin D tablets. They may also ask you to take bone-strengthening drugs called bisphosphonates or a drug called denosumab (Prolia®).

Mood changes

You may have mood changes and feel emotional or anxious. This can be a side effect of hormonal therapy, but can also be because you are coping with advanced cancer. Tell your cancer doctor or nurse if these feelings are difficult to cope with. They can support you or refer you to a doctor or counsellor who specialises in emotional support. They may also prescribe drugs to help if needed.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is given to men when they are first diagnosed with advanced prostate cancer, together with hormonal therapy. It may also be used to treat cancer that is no longer being controlled by hormonal therapy.

The aim of chemotherapy for advanced prostate cancer is to control the cancer. This will help to relieve symptoms and improve quality of life.

The most commonly used chemotherapy drug to treat prostate cancer is docetaxel (Taxotere®). Other drugs that may be used are:

- cabazitaxel (Jevtana®)
- mitoxantrone.

> 'I have had surgery, radiotherapy, hormonal therapy, and my last treatment was chemotherapy. I knew chemotherapy wouldn't be a cure but, so far, it has had the best effect on my PSA of all the treatments.'
>
> **Jim**

How chemotherapy is given

The chemotherapy drugs are given into a vein (intravenously). The drugs get into the blood and can reach cancer cells all over the body.

You can have chemotherapy drugs through:

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

You usually have chemotherapy as several sessions of treatment. Each session is followed by a rest period of a few weeks. Chemotherapy and the rest period make up a cycle of treatment. Your cancer doctor will explain how many cycles you need to treat the cancer.

On the next page, we have included a picture of someone having chemotherapy.

Having chemotherapy

Side effects

The side effects you get will depend on the chemotherapy drugs you are having. Different drugs cause different side effects. You may get some of the side effects we mention here, but you are unlikely to get all of them. Some side effects are mild and can be treated easily. Your doctor, nurse or pharmacist may prescribe drugs to help control them. Most side effects stop or gradually get better when chemotherapy is over.

Risk of infection

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

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

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

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more chemotherapy. If your white blood cell count is low, your doctor may delay your treatment for a short time.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you cannot explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Feeling sick

You may feel sick in the first few days after treatment. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Loss of appetite

This treatment can affect your appetite. Don’t worry if you don’t eat much for a day or two. But if your appetite does not come back after a few days, tell your nurse or dietitian. They will give you advice. They may give you food or drink supplements.

Sore mouth

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

If your mouth is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth.

Hair loss

Your hair will get thinner or you may lose all the hair from your head. You may also lose your eyelashes, eyebrows or other body hair. Hair loss usually starts after your first or second treatment. Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. It is important to cover your head to protect your scalp when you are out in the sun.

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

Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

Diarrhoea

If you have diarrhoea, contact the hospital for advice. Try to drink at least 2 litres (3½ pints) of fluids every day. It can help to avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods.

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells. Doctors use it in different situations to treat advanced prostate cancer. It is most often used to shrink cancer that has spread to the bones. It is used to strengthen the bone and reduce pain. This helps you to keep you as active as possible without being in pain. Sometimes treatment to the bones may also help you live longer.

Radiotherapy can also help to relieve pain if the cancer is in a lymph node (see pages 14 to 15) or pressing on the back passage (rectum). It can also help control bleeding in the urine (pee). Radiotherapy to relieve your symptoms is called palliative radiotherapy.

Radiotherapy to treat advanced prostate cancer can be given in two ways:

- as external beam radiotherapy – where radiotherapy is given from outside the body (externally) from a radiotherapy machine
- as an injection of a radioisotope liquid into a vein.

Your pain may get better within a couple of days of treatment, or it may take a couple of weeks for pain to improve. It may be up to 6 weeks before you feel the full benefit. Sometimes, the pain may get worse before it gets better.

You will need to keep taking painkillers during this time. Tell your cancer doctor or nurse if the pain gets worse, so they can increase your painkillers. When the treatment has worked, they can reduce them.

External beam radiotherapy for advanced prostate cancer

You can have external beam radiotherapy as an outpatient in the radiotherapy department. Some people may need to stay in hospital while they have it. Radiotherapy is given using a machine that is like a big x-ray machine. This is called a linear accelerator (often called a LINAC).

You may have external beam radiotherapy as a single treatment or as a few sessions over a few weeks.

At the beginning of a treatment session (called a fraction), the radiographer will make sure you are in the correct position on the couch and that you are comfortable. Radiotherapy is not painful. But you have to lie still during the treatment. You may want to take your painkillers before you have it.

When everything is ready, the radiographer leaves the room so you can have 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.

Your cancer doctor, nurse or radiographer will explain your treatment and its possible side effects. They can give you advice to help you cope with any side effects. They can also help answer any questions you may have.

Side effects

The side effects of palliative radiotherapy are usually mild. They will depend on the area of the body that is being treated.

Feeling very tired is a common side effect. This should gradually improve a few weeks after treatment finishes. Try to pace yourself and get as much rest as you need. It helps to balance this with some gentle exercise, such as short walks, if possible.

You may feel sick if the area treated is close to your tummy, for example the ribs or spine. Your doctor can prescribe anti-sickness drugs to control any sickness.

If you only have 1 or 2 treatment sessions, you may have flu-like symptoms for a few days afterwards.

Always tell your nurse or radiographer about any side effects. There are usually ways to treat or manage them.

We have more information about the side effects of radiotherapy in our booklet **Understanding radiotherapy** – see page 122 for ways to order this.

Spinal cord compression

If a tumour is close to or pressing on the spinal cord, it is called spinal cord compression. Doctors can treat this with a short course of external radiotherapy to the spine. You may have one single treatment or up to 2 weeks of radiotherapy.

Spinal cord compression causes symptoms, such as:

- a new pain in your neck or back
- numbness or pins and needles in your feet or hands
- difficulty walking.

Spinal cord compression is not common, but it needs to be treated quickly to prevent permanent damage to the nerves. Always tell your doctor straight away if you have any of these symptoms.

> ‘Because I had a tumour on my spine, I had several sessions of radiotherapy. The treatment was successful as it helped reduce my back pain significantly.’
>
> **Alan**

Radioisotope therapy

Radioisotope therapy can be used to treat prostate cancer that has spread to the bones.

This treatment uses radioactive substances known as radioisotopes. Cancer cells absorb radioisotopes more than normal cells do. This means they get a higher dose of radiation to destroy them. All the bones affected by cancer will be treated. So it can be very helpful if the cancer is in different areas of bone.

You may be given a radioisotope if hormonal therapy is no longer helping to control prostate cancer that has spread to the bone.

The radioisotopes that can be used are:

- radium-223 (Xofigo®) – this is usually given once a month for 6 treatments
- strontium-89 – this treatment can be repeated if you need it.

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

You have the treatment as an outpatient in the radiotherapy department and go home on the same day. The hospital will give you information about this treatment.

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

After you have had the injection, you will have some radioisotopes in your poo (bowel movement), urine and blood. Because of this, there are certain precautions you need to take when you go to the toilet. This is to protect yourself and others from being exposed to the radiation. You only need to do this for a week.

For example, they will ask you to sit down to use the toilet rather than use a urinal. It is still safe for you to be with other people, including children. The hospital staff will explain more about this.

Side effects

The side effects of radioisotope therapy are usually mild. You may have some diarrhoea or feel slightly sick. Your doctor can prescribe drugs to control these if needed.

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

Surgery

Some men are offered surgery for advanced prostate cancer. The aim of the surgery is to help with symptoms rather than to treat the cancer.

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

Subcapsular orchidectomy

This is an operation to remove part of the testicles. The aim is to reduce the level of the male hormone testosterone in the body.

It is not commonly used because hormonal therapy treatment is usually very effective at lowering the testosterone levels.

We have more information about hormonal therapies on pages 49 to 59.

Transurethral resection of the prostate (TURP)

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

During the procedure, a thin tube that contains a cutting instrument and a tiny camera is passed through the urethra and into the prostate. The cutting instrument is used to shave off the inner area of the prostate and unblock the urethra.

This can be done under a general anaesthetic while you are asleep. Or you may have a local anaesthetic using a spinal anaesthetic (epidural). An epidural temporarily numbs the lower part of your body using an injection of anaesthetic into the spine. You are awake, but you will not feel anything.

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

After your TURP

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

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

Catheter

You will have a tube (catheter) to drain urine from the bladder into a bag. After a TURP, your urine will have blood in it for a while. To stop blood clots blocking the catheter, fluid is passed into the bladder and drained out through the catheter. This is called bladder irrigation. The blood will slowly clear from your urine, and then the catheter can be taken out.

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

You may need to keep the catheter in for a while after you go home. This is because swelling caused by the surgery may make it difficult for you to pass urine. The nurse will show you how to look after your catheter before you leave the hospital. They can also organise for a district nurse to visit you at home to help with any problems. Once the swelling goes down, the catheter can be removed.

If you go home with a catheter, you may have bladder spasms. These are caused by the catheter irritating your bladder. The spasms can cause urine to bypass your catheter, so you leak urine at times. These spasms are normal, but if they last a long time and are frequent, tell your doctor or nurse. Some men find them uncomfortable.

Pain

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

Ejaculating into the bladder

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

Erection problems

Some men may have problems getting an erection after having a TURP (called erectile dysfunction, or ED). This depends on whether you had problems getting an erection before having this operation. Your surgeon may be able to explain more about your risk of erection problems.

We have more information about managing erection problems on pages 95 to 98.

Difficulties passing urine

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

Percutaneous nephrostomy and JJ stent

In some men, the tubes that connect the kidneys to the bladder (ureters) may get blocked by the prostate cancer. If this happens, you may be offered one of the following types of surgery:

- Percutaneous nephrostomy – The doctor puts a tube into the kidney that goes into a bag that sits outside on the skin. Urine can then drain into the bag.
- JJ stent – This is a fine tube that is put into the ureter. The JJ stent opens up the ureter so urine can flow freely through it.

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

Strengthening a weakened bone

In some men, advanced prostate cancer that has spread to the bones may cause problems that need treating. If there is a risk of a bone breaking, your doctor may advise surgery to strengthen or repair the bone.

Our booklet **Understanding secondary cancer in the bone** has more information – see page 122 for ways to order this.

Going home after surgery

If you think you might have 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.

Social workers can offer practical advice and valuable support to you and your family. If you would like to talk to a social worker, ask your nurse or doctor to arrange this for you.

Before you leave hospital, you will be given an appointment at an outpatient clinic for your post-operative check-up. This is a good time to talk about any problems you may have.

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.

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)**. We can send you a free copy (see page 122).

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.

> ‘Before my diagnosis, I enjoyed cycling. The thought that I may not be able to carry on with this was very upsetting. But I am cycling at about the same levels as before my diagnosis.’

Alan

COPING WITH ADVANCED PROSTATE CANCER

Managing symptoms

Advanced prostate cancer may cause symptoms that can be difficult to cope with. But there are different ways they can be managed or controlled. Treatments for the cancer can also improve symptoms. But they sometimes take a couple of weeks to work.

Different members of your cancer team can support you. You may see a doctor or nurse who specialises in pain and symptom control. They are sometimes called palliative care specialists.

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

> ‘It is important that you keep active, even if it’s not as active as you used to be. It is very easy to think, “I’ve got to do less and less”. Going for short walks is important.’
>
> **Nathan**

Tiredness

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

- Pace your everyday activities and save energy for things you want to do.
- Accept offers of help from others, or ask for help when you need it.
- Try to be more physically active to improve your energy levels – for example, by taking regular short walks.
- Eat healthily to give you more energy and help you to feel better.
- Try some complementary therapies such as relaxation techniques, which may help you to feel less anxious and tired.

If you are having problems getting around, ask to see a physiotherapist or occupational therapist. Using a walking aid may allow you to move more easily.

Tell your doctor or nurse if you are very tired. They can test your blood to make sure you do not have anaemia (low red blood cells). This can make you feel tired and sometimes breathless. Some men may need a blood transfusion to improve this.

Our booklet **Coping with fatigue** has more information – see page 122 for ways to order this.

Pain

Always tell your doctor or nurse if you have pain. There are different painkillers that work in different ways. You can take painkillers:

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

Try to take your painkillers regularly, even if you are not in pain when the next dose is due. This will help prevent pain from coming back.

If your painkillers are not working well, tell your doctor. They can increase the dose or change the painkiller to one that works better for you.

There are special NHS pain clinics run by doctors and nurses who are experts in treating pain. If there are difficulties in controlling your pain, you can ask your doctor to refer you to a clinic.

Treating bone pain

The most common place for advanced prostate cancer to spread to is the bones. There are different ways bone pain can be controlled. You may be given:

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

Radiotherapy is very effective at easing bone pain but can take a few weeks to work. Take your painkillers regularly until the radiotherapy works.

Bisphosphonates

Drugs such as zoledronic acid (Zometa®) help to:

- strengthen bones
- lower the risk of fractures
- reduce bone pain.

You can have bisphosphonates as a drip (infusion) into a vein. You have this in the outpatient department every 3 to 4 weeks. Bisphosphonates can also reduce high levels of calcium in the blood (hypercalcaemia) caused by the cancer in the bones.

Denosumab

Denosumab is a type of targeted therapy drug that can also be used to help strengthen bones. It is given as an injection just under the skin (subcutaneously) every 4 weeks. Your doctor or nurse can give you more information.

Our booklet **Managing cancer pain** has more information – see page 122 for ways to order this.

Treating bone problems

In some men, secondary cancer in the bones may cause problems that need treatment. There are ways in which they can be managed.

Hypercalcaemia

Secondary cancer in the bones may cause calcium to be released from the bones into the blood. This is not common in prostate cancer.

If you have high levels of calcium in the blood, it can make you feel sick, thirsty and drowsy. You may also be constipated. Tell your doctor or nurse if you have these symptoms. It is important hypercalcaemia is diagnosed quickly so that it can be treated.

Your nurse or doctor will give you a drip (infusion) of fluids to help to flush out the extra calcium from your body. They also give you bisphosphonates as a drip to lower the calcium levels. Your symptoms should go away within a couple of days.

Strengthening a weakened bone

If there is a risk of a bone breaking, your doctor may advise surgery to strengthen or repair the bone. This is done under a general anaesthetic.

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

Some men have surgery to the spine or have a hip joint that has been damaged by the cancer replaced.

You may need to stay in hospital for a week or longer after surgery so you can fully recover. Most men can get up and start walking a couple of days after their operation.

You may have radiotherapy before or after surgery. This can help repair the bone or try to get rid of any cancer cells.

Malignant spinal cord compression

Malignant spinal cord compression (MSCC) happens when cancer cells grow in, or near to, the spine and press on the spinal cord and nerves.

Symptoms of MSCC include:

- back or neck pain – the first symptom is often severe pain that comes on gradually
- numbness or pins and needles in your toes, fingers or buttocks
- feeling unsteady on your feet
- bladder or bowel problems.

If you notice any of these symptoms, contact your cancer doctor, nurse or GP straight away so they can do some tests.

The earlier treatment starts, the more likely it is to be effective. Steroids, radiotherapy and surgery may all be used, depending on your situation. Your doctor will talk to you about any possible risks first.

We have more information about secondary cancer in the bones and MSCC that we can send you. Call us on **0808 808 00 00**.

Bladder or bowel problems

If you have bladder problems, such as needing to pee urgently or leakage, there are different things that can help. Your nurse can advise you or put you in touch with a continence service. There are different pads you can use and treatments that may help. The Bladder and Bowel Community has useful information (see page 127 for contact details).

Some men who have pelvic radiotherapy may develop bowel problems, such as diarrhoea, much later. There are different ways to manage the late effects of pelvic radiotherapy. Your doctor can prescribe drugs to help control diarrhoea.

You may also have constipation. This can be due to:

- certain painkillers
- being less active than usual
- not eating enough high-fibre foods.

There are things you can do to help, including:

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

Your doctor may need to prescribe you medicine (laxative) to make your bowels work.

Macmillan toilet card

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

We hope it allows you to get access to a toilet without any awkward questions. But we cannot guarantee that it will work everywhere. Call **0808 808 00 00** or visit **be.macmillan.org.uk** to order a toilet card.

Eating difficulties

If you have eating difficulties or are worried about losing weight or gaining weight, there is lots of information to help you. It is a good idea to ask your nurse or a dietitian for advice.

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

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

Complementary therapies

Some people find that complementary therapies, such as relaxation, gentle massage or aromatherapy, help them to feel better and more in control. They may reduce symptoms of anxiety or help ease pain.

Let your doctor or nurse know if you plan to use any complementary therapies. They can advise you if a complementary therapy is suitable for your situation. It is also important to use a qualified therapist and tell them about your diagnosis.

Our booklet **Cancer and complementary therapies** has more information – see page 122 for ways to order this.

Sex and relationships

Treatments for prostate cancer can affect your sex life and your relationships. Treatments may have a direct effect on your sex life. Symptoms of the cancer or its treatments, such as tiredness or discomfort, can make it difficult to have sex. Feelings such as anxiety or sadness can also affect how you feel about 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. It 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.

Being more physically active, eating healthily and managing your weight may help to improve body image concerns. Ask your doctor or nurse for advice.

Our booklet **Body image and cancer** has more information – see page 122 for ways to order this.

> ‘My loss of sex drive has been restored, but not to the same level before treatment. But I have discovered that mutual affection and love do not decrease like sexual urge.’
>
> **Percy**

Sexual difficulties

The difficulties you have will depend on the treatment you have. Some men may already have sexual difficulties because of previous prostate treatments, other medical conditions or their age.

Your doctor or nurse will explain the effects of your treatment on your sex life. For some men, this may be an important factor in making treatment decisions.

Effects of treatments may cause:

- a reduced or loss of interest in sex
- difficulties getting or keeping an erection (erectile dysfunction, or ED)
- difficulties having an orgasm or ejaculating
- the penis and testicles to get smaller if you are taking hormonal therapy for a long time.

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 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 also 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 127 for contact details).

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 – call **0345 3 30 30 30**.

Managing sexual difficulties

Most men with advanced prostate cancer have hormonal therapy (see pages 49 to 59). Loss of sex drive and erection difficulties are common side effects of most of these drugs.

There are no treatments that increase sexual desire while you are on hormonal therapy. When you stop taking hormonal therapy, many side effects gradually go away. It is sometimes possible to have breaks in hormonal therapy (called intermittent hormonal therapy). This may help some men.

Treatments for erectile dysfunction (ED) may help some men get an erection. But they will not increase desire. Your doctor or nurse will give you information about these. Many treatments work by increasing the blood supply to the penis.

If you need support coping with sexual difficulties, your nurse or doctor can give you information. They can also refer you to specialist support services.

Tablets

Tablets you take before sex are a common treatment for ED. You need to be sexually stimulated to get an erection first. If you have heart problems or are taking certain drugs, these tablets may not be recommended for you. Your GP will explain their side effects. Tablets include sildenafil (Viagra®), vardenafil (Levitra®), tadalafil (Cialis®) and avanafil (Spedra®).

Injections

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 causing an erection in 5 to 20 minutes. A healthcare professional will give you the first dose and teach you how to do this yourself.

Pellets or creams

Pellets or creams can be put into the opening of the penis with an applicator. The cream or pellet is absorbed into the penis and produces an erection.

Pumps

Vacuum pumps can also be used to produce an erection. They pull blood into the penis 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.

Our booklet **Cancer and your sex life – information for men** has more information. See page 122 for ways to order this.

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.

If you are single

If you are not in a relationship, it is natural to worry about meeting a new partner or about your sex life. You may need some time to come to terms with what has happened.

It may help to talk to a counsellor or sex therapist. The College of Sexual and Relationship Therapists (COSRT) has a list of nationwide counsellors and therapists who can offer advice and support – 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** has more information – see page 122 for ways to order this.

> 'I would never have imagined myself going to a support group. I thought it would just be a sad group of people making each other sadder. I now go to three!'
>
> **Jim**

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.

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 122 for ways to order these booklets.

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

> 'The NHS is the technical side of my care, but my wife as my carer is totally critical. Her task is 24 hours a day! I can never thank her enough.'
>
> **Jim**

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.

Who can help?

Many people are available to help you and your family.

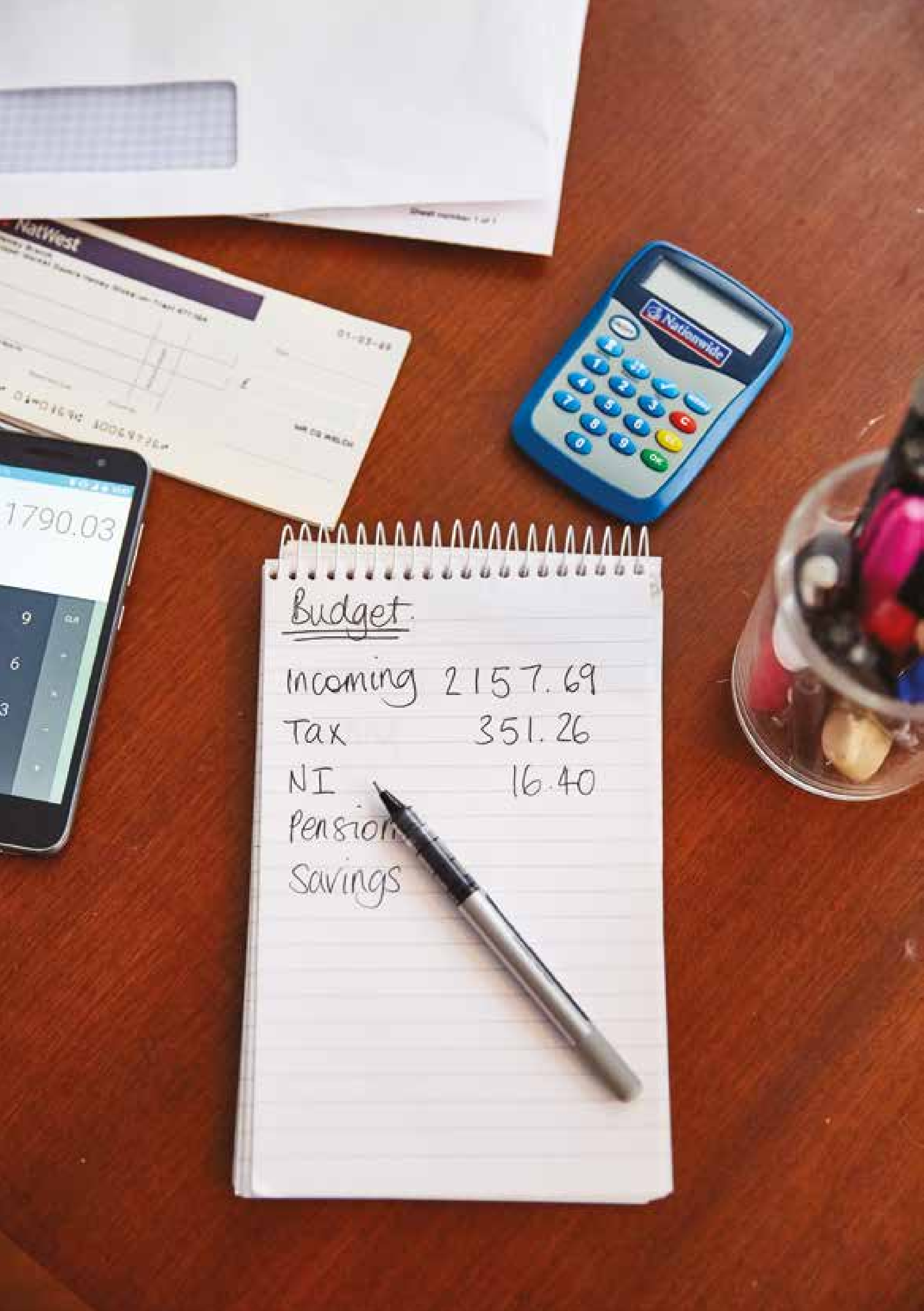
District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.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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 £380, but this may change from time to time. 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 122 for ways to order them. 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 131 for contact details.

Our booklet **Help with the cost of cancer** has lots more information – see page 122 for ways to order this.

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 122 for ways to order them.

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 122 for ways to order this.

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 7 days a week, 8am to 8pm. Our cancer support specialists can:

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

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

Information centres

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

Visit one to get the information you need, or if you'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
info@orchid-cancer.org.uk
www.orchid-cancer.org.uk
Funds research into men's cancers and their diagnosis, prevention and treatment. Offers free information leaflets and fact sheets, and runs an enquiry service supported by Orchid male cancer information nurses.

Prostate Cancer UK

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.

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.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk

Has 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.

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.

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

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Equipment and advice on living with a disability

British Red Cross

Tel 0344 871 11 11
Textphone 020 7562 2050
Email
contactus@redcross.org.uk
www.redcross.org.uk

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Email
enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Disabled Living Foundation (DLF)

Helpline 0300 999 0004
(Mon to Fri, 10am to 4pm)
Email info@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

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 their 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.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline
(England, Scotland, Wales)
0808 808 7777
(Mon and Tue, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
www.carersuk.org

Offers information and support to carers across the UK.

Advanced cancer and end-of-life care

Marie Curie

Helpline 0800 090 2309
(Mon to Fri, 9am to 6pm,
Sat, 11am to 5pm)
www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care across the UK.

Bereavement support

Cruse Bereavement Care

Helpline 0808 808 1677
(Mon and Fri, 9.30am to 5pm,
Tue to Thu, 9.30am to 8pm)
Email helpline@cruse.org.uk
www.cruse.org.uk

Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website.

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

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

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

The booklet explains the signs and symptoms of advanced 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** (7 days a week, 8am to 8pm) 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.

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MAC11686_E05_N. Next planned review 2020.
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