A practical guide to understanding cancer

UNDERSTANDING LOCALLY ADVANCED PROSTATE CANCER
Contents

About prostate cancer
Treating locally advanced prostate cancer
After treatment
Your feelings and relationships
Work and financial support
Further information
About this booklet

This booklet is for men who have been diagnosed with locally advanced prostate cancer. This is when prostate cancer has started to spread beyond the prostate gland and may be affecting surrounding structures.

We can’t advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

Throughout this booklet we’ve included quotes from people affected by prostate cancer. Some are from members of our online community at macmillan.org.uk/community. Others are from people who have shared their experiences with us by becoming a Cancer Voice – find out more at macmillan.org.uk/cancervoices.

We hope this booklet answers some of your questions and helps you deal with some of the feelings you may have. We’ve also listed other sources of support and information. Turn to pages 99–107 for some useful addresses and websites, and page 108 to write down questions for your doctor or nurse.

If you’d like to discuss this information, call the Macmillan Support Line free on 0808 808 00 00, Monday–Friday, 9am–8pm. If you’re hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit macmillan.org.uk.

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.
What is cancer?

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

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more and more abnormal cells. These eventually form a **lump (tumour)**.

Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a **biopsy**. The doctors examine the sample under a microscope to look for cancer cells.
A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

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 10–11). 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.

We have a video on our website that explains how cancer develops. You can watch it at macmillan.org.uk/aboutcancer
The prostate gland

The prostate is a small gland only found in men. It’s about the size of a walnut and gets a little bigger with age. It surrounds the first part of the tube (urethra) that carries urine from the bladder along the penis.

The male sex organs and surrounding structures
The prostate produces a thick, white fluid that mixes with the sperm from the testicles to make semen. It also produces a protein called prostate-specific antigen (PSA) that turns the semen into liquid.

The prostate gland is surrounded by a sheet of muscle and a fibrous capsule. The growth of prostate cells and the way the prostate gland works are dependent on the male sex hormone testosterone. This is produced in the testicles.

The back of the prostate gland is close to the rectum (back passage). Near to the prostate are collections of lymph nodes. These are small glands, each about the size of a baked bean. They are part of the lymphatic system (see pages 10–11).
The lymphatic system

The lymphatic system helps to 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.

Sometimes prostate cancer cells can spread to the lymph nodes near to the prostate gland or to more distant lymph nodes. Locally advanced prostate cancers may have spread to nearby lymph nodes.
Prostate cancer

Prostate cancer is the most common type of cancer in men. Over 41,000 men in the UK are diagnosed with prostate cancer each year. It usually affects men over 50 and is rare in younger men.

It differs from most other cancers in the body, in that small areas of cancer within the prostate are very common. It may also stay dormant (inactive) for many years.

Most prostate cancers grow very slowly. But in some men, prostate cancer can grow more quickly and in some cases may spread to other parts of the body, particularly the bones.
Risk factors and causes

The number of men who are diagnosed with prostate cancer in the UK has increased in recent years. It is thought that this is because more men are having tests that detect very early prostate cancers that would previously not have been found. These tests include the PSA test. This is a blood test that measures a type of protein called prostate-specific antigen (PSA). A small amount of PSA is normally found in the blood, but men who have prostate cancer tend to have a higher level of PSA in their blood.

If you’d like to know more about PSA testing we can send you our free booklet Understanding the PSA test.

The causes of prostate cancer are still unknown but there are some risk factors that increase a man’s chance of developing the disease.

Age

This is the strongest risk factor for prostate cancer. The risk increases with age. Men under 50 have a much lower risk of prostate cancer, but their risk increases as they get older. Approximately 75% of prostate cancers (75 in 100) are diagnosed in men aged 65 and over.

Ethnicity

Some ethnic groups have a greater chance of developing prostate cancer than others. For example, black African and black Caribbean men are more likely to develop prostate cancer than white men. Asian men have a lower risk of developing it. The reason for this is unknown.
**Family history**

Most prostate cancers aren’t caused by inherited cancer genes and most men who get prostate cancer don’t have a family history of it.

If you’ve just had one relative who developed prostate cancer at an older age, your risk is unlikely to be very different from other men the same age as you. But sometimes prostate cancer can run in families.

In general, the more men in a family who have been diagnosed with prostate cancer, the younger they were when diagnosed and the more closely related they are, the more likely it is there’s a family link.

It is thought that a man’s risk of developing prostate cancer is higher if they have:

• one first-degree relative (a father, brother or son) who developed prostate cancer at or under the age of 60

• two or more close relatives on the same side of the family who have had prostate cancer (a close relative is a father, brother, son, grandfather, uncle or nephew).

Experts think that 5–15% of prostate cancers (5–15 in 100) are linked to inherited gene changes that increase the risk of developing it.
There isn’t one specific ‘prostate cancer gene’ that explains most of the cases of hereditary prostate cancer. Instead it is thought that variations in several genes may be involved. In a small number of men, prostate cancer is linked to the breast and ovarian cancer genes BRCA1 and, particularly, BRCA2. So if you have a relative with prostate cancer and there is also a strong history of breast or ovarian cancer in the same side of the family, this may be due to a BRCA1 or BRCA2 gene.

If you’re concerned about your family history of prostate cancer, we can send you our leaflet *Are you worried about prostate cancer?* We also have a booklet called *Cancer genetics – how cancer sometimes runs in families*. Call 0808 808 00 00 to order these.

**Diet**

Some evidence suggests that diet can affect your risk of prostate cancer, but this is not completely clear. Current thinking suggests that a diet high in animal fats may increase your risk of developing prostate cancer. Animal fats can be found in red meat (such as beef, lamb and pork) and dairy produce (including butter, full-fat milk, cheese, eggs and cream).

Eating a healthy, balanced diet that’s high in fibre and low in fat and sugars may reduce your risk of getting certain types of cancers and other illnesses.
Staging and grading

Staging
The stage of a cancer is a term used to describe its size and whether it has spread. A commonly used staging system is the TNM staging system.

TNM staging
The TNM system assesses the tumour, the lymph nodes and whether the cancer has spread (metastasised).

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

**T1** – The tumour is within the prostate gland. It is too small to be detected during a rectal examination, but may be picked up through tests such as a PSA test, a biopsy or a transurethral resection of the prostate gland (TURP). This is an operation to make passing urine easier by removing part of the prostate gland. There are generally no symptoms with T1 tumours.

**T2** – The tumour is still within the prostate gland but is large enough to be felt during a digital rectal examination, or it shows up on a scan. Often there are no symptoms.

The T2 stage is divided into:

- **T2a** – The tumour is only in one half of one of the two lobes that make up the prostate gland.

- **T2b** – The tumour is in more than one half of one of the lobes in the prostate gland.
• **T2c** – The tumour is in both lobes of the prostate gland.

T1 and T2 tumours are known as early (localised) prostate cancer.

**T3** – The cancer has begun to spread through the capsule that surrounds the prostate gland. The T3 stage is divided into:

• **T3a** – The tumour has broken through the capsule but is not affecting the surrounding structures.

• **T3b** – The tumour has spread into the glands that produce semen (seminal vesicles). These are very close to the prostate gland and sit just underneath the bladder.

**T4** – The tumour has started to spread into nearby parts of the body such as the bladder or rectum.

T3 and T4 tumours are known as locally advanced prostate cancer because the cancer has started to spread outside the prostate gland and may be invading surrounding structures.

If the cancer has spread to other parts of the body, it’s known as metastatic, secondary, or advanced prostate cancer.

**N stands for nodes**

This describes whether there are any lymph nodes near the prostate gland that have cancer in them. The N may have an X or a number written next to it, which gives extra information about the nodes:

**NX** – The lymph nodes were not examined.

**N0** – The lymph nodes were examined but no cancer was found.

**N1** – Cancer was found in the lymph nodes.
**M stands for metastasis**

Metastasis means that the cancer has spread to other parts of the body, such as the bones.

The M may have a number written next to it, which gives extra information about where the cancer has spread to:

- **M0** – The cancer has not spread to other parts of the body.
- **M1** – The cancer has spread to another part of the body, such as the bones, lung or liver.

You can talk to your doctors about your TNM staging. They will be able to explain it to you. Our cancer support specialists on 0808 808 00 00 can also tell you more about TNM staging.
Grading

The grade of a cancer gives an idea of how quickly it might grow. Prostate cancer is graded according to how the cancer cells look when the biopsy sample is looked at under the microscope.

The Gleason system is the most commonly used grading system. It looks at the pattern of cancer cells within the prostate. There are five patterns, which are graded from 1–5.

1 is very similar to normal prostate tissue, whereas 5 is very different to normal tissue. Only grades 3–5 are cancer.

The biopsy samples are each graded and the most common pattern followed by the highest grade of the other patterns are added together to get a Gleason score of 6–10.

Low-grade cancers with a Gleason score of 6 are usually slow-growing and less likely to spread. High-grade cancers (Gleason score of 8–10) are more likely to grow quickly and to spread.
TREATING LOCALLY ADVANCED PROSTATE CANCER

Treatment overview 22
External-beam radiotherapy 28
Hormonal therapy 36
Watchful waiting 42
Less common treatments 44
Research – clinical trials 58
Treatment overview

This section tells you about the different treatments for locally advanced prostate cancer. There’s a lot of information in this section so take your time when reading it. If you know what treatment you are having you may want to read just that section.

Main treatments

The main treatment options for locally advanced prostate cancer include external-beam radiotherapy, hormonal therapy and watchful waiting.

Most men with locally advanced prostate cancer will need a combination of treatments. This is often known as multimodal treatment.

External-beam radiotherapy (see pages 28–35)
This uses high-energy x-rays to destroy the cancer cells.

External-beam radiotherapy is usually given with hormonal therapy. It may also be given after surgery or on its own.

Hormonal therapy (see pages 36–41)
Hormones control the growth and activity of normal cells. In order to grow, prostate cancer depends on the hormone testosterone, which is produced by the testicles. Hormonal therapies reduce the amount of testosterone in the body.

Hormonal therapy is usually given with radiotherapy but it can be given on its own. Giving hormonal therapy plus radiotherapy makes the treatment more effective. Hormonal therapy is usually given before, during and after radiotherapy.
Watchful waiting (see pages 42–43)
This is when doctors monitor your cancer. You will not start treatment to control your cancer unless it progresses. It’s a way of avoiding treatment for as long as possible.

If you are an older man with no symptoms from your cancer or you have medical problems, you may be advised to have watchful waiting. This is because you may live just as long without having any active treatment. And for some men the side effects of treatment may be worse than the effects of the cancer.

If during watchful waiting your cancer starts to progress or you develop symptoms, such as problems passing urine, you will usually be offered hormonal therapy to help control the cancer.

Less common treatments

Brachytherapy (see pages 44–47)
Locally advanced prostate cancer can also be treated with brachytherapy (also known as internal radiotherapy). It’s usually given with external-beam radiotherapy. Brachytherapy is only carried out in specialist hospitals.

Surgery (see pages 49–57)
Occasionally, surgery to remove the prostate gland may be carried out to try to stop the cancer spreading. This is called a radical prostatectomy. It’s not commonly used to treat locally advanced prostate cancer. This is because it may not be possible to remove all the cancer cells that have spread outside the prostate gland.

If you do have surgery, you will usually have other treatments, such as radiotherapy, afterwards. This is to reduce the risk of the cancer coming back. Your doctor will talk to you about this before your surgery.
Sometimes other types of surgery are carried out to relieve symptoms or reduce levels of the male hormone testosterone in the body.

**How your treatment is planned**

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

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

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

The team will look at different factors to help decide which treatments are likely to be best for you:

- your general health
- the stage of the prostate cancer
- your Gleason score
- your PSA level
• the likely side effects of treatment

• whether you’ve had treatment before.

After the MDT has met, your specialist will talk to you about the best treatment for your situation and any likely side effects. They may offer you a choice of treatments, which they will explain to you. They will want to know your views about the treatment(s) and its side effects before a treatment decision is made.

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.

Choosing between two or more treatments

In some situations, your doctor may ask you to choose between two or more types of treatment that are equally effective.

Before making your decision, make sure you have information about the different treatments being offered to you. Ask your doctor or nurse about what the treatment involves, its advantages, disadvantages and possible side effects. This will help you decide which treatment is best for you. Remember that everyone reacts differently to cancer treatment. This means that it is impossible
for doctors to know if you will or won’t be affected by the side effects of each treatment. You may also want to ask your doctor or specialist nurse for some time to think about your options.

We’ve highlighted the advantages and disadvantages of individual treatments for locally advanced prostate cancer in green boxes at the end of each treatment section.

You may find our booklet *Making treatment decisions* helpful. Call 0808 808 00 00 to order a copy.

‘The disturbance in my life – and the discomfort experienced through the examination and the treatment – pale into insignificance when I weigh out the benefits of receiving the treatment.’

Daniel

**Giving your consent**

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment.
No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don’t understand what you’ve been told, let the staff know straightaway, so they can explain again. Some cancer treatments are complex, so it’s not unusual to need repeated explanations. It’s a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it’s important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can’t make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don’t have it. It’s essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don’t have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.
External-beam radiotherapy treats cancer by using high-energy x-rays to destroy the cancer cells, while doing as little harm as possible to normal cells. It’s the most common way of giving radiotherapy for locally advanced prostate cancer. It’s usually given with hormonal therapy (see pages 36–41).

The treatment is given in the hospital radiotherapy department. It’s usually given as daily sessions from Monday–Friday, with a rest at the weekend. The course of treatment may take up to eight weeks.

Planning external-beam radiotherapy

External-beam radiotherapy is planned by an oncologist (see page 24). Planning is a very important part of radiotherapy and may take one or two visits to hospital. The treatment is carefully planned to make sure it is as effective as possible.

As part of your planning, you’ll be asked to have a CT scan, which takes x-rays of the area to be treated.

You can read more about what a CT scan involves in our booklet Having tests for prostate cancer.

Before your CT scan you may need to follow a special diet. Occasionally, you may be asked to have an enema. This involves having a small amount of liquid passed into your rectum via a thin tube. The liquid will help you to empty your bowel before the CT images are taken. Having an empty bowel gives very clear CT images and this helps your radiographers plan your treatment.
Just before the scan you may also be asked to drink a few glasses of water to fill up your bladder. This will also help to give clear CT images. If you need to follow a special diet, have an enema or drink fluids before your scan, you will be given written information about this.

During your planning, tiny tattoos or permanent marks may be drawn on your skin. These show where the radiotherapy is to be given. They help the radiographers position you accurately and set up where the treatment will be given. The marks are usually permanent but they are the size of pinpoints and will only be done with your permission. Having the tattoos done can cause some discomfort but this won’t last long.

Some men may have very small gold grains put into their prostate gland during an outpatient procedure. The prostate gland moves when you breathe or when your bowel is full and the gold grains act as markers to help your oncologists plan each of your daily treatments accurately. This helps to reduce side effects and damage to organs that are close to the prostate gland. There are other ways of planning your treatment accurately. Your hospital team can tell you more about the technique they use.

Radiotherapy can make your skin sore. During your planning appointments you’ll be given advice about how to look after your skin.

**Treatment sessions**

At the beginning of each session of radiotherapy, the radiographer will position you carefully on the couch and make sure you are comfortable. During your treatment you’ll be alone in the room, but you can talk to the radiographer, who will watch you from the next room. Radiotherapy is not painful, but you have to lie still for a few minutes during the treatment.
Ways of giving external-beam radiotherapy
There are different ways of giving external radiotherapy. All the current ways of giving radiotherapy aim to reduce damage to healthy tissues and side effects.

Conformal radiotherapy uses a device inside the radiotherapy machine to shape the radiation beams to fit the treatment area.

Intensity-modulated radiotherapy (IMRT) shapes the radiotherapy beam more than conformal radiotherapy. It allows different doses of radiotherapy to be given to different parts of the treatment area. A TomoTherapy® machine combines IMRT with a CT scan so each treatment is very accurate.

Your cancer specialist can tell you more about the type you are having. We also have more information about IMRT.

Short-term side effects
Most of the side effects of radiotherapy gradually disappear once treatment has finished. Your cancer specialist, nurse or radiographer can tell you what to expect. Tell them about any side effects so that they can help manage them.

Radiotherapy causes tiredness, especially if you’re travelling a long way for treatment each day. Try to make sure you get enough rest, but try to balance this with regular, gentle exercise, which will give you more energy.

We can send you a booklet about coping with tiredness. Call 0808 808 00 00 to order a free copy.
Radiotherapy to the prostate area may irritate the rectum, cause soreness around the anus, and cause diarrhoea. Your doctor can prescribe medicines to reduce these effects and you may be advised to make some changes to your diet.

Radiotherapy can also cause inflammation of the bladder (cystitis). You may want to pass urine more often or you may have a burning feeling when you pass urine. Your doctor can prescribe medicines to reduce this. Make sure you drink plenty of fluids. These effects usually disappear gradually a few weeks after the treatment has finished.

A very small number of men may have difficulty passing urine and may need a urinary catheter put in. This is a tube that is placed inside the bladder to help the urine drain out of the body. Very rarely, some men may experience leakage or incontinence of urine.

Radiotherapy to the pelvis may make some of your pubic hair fall out. When you’ve finished your treatment, the hair will grow back. It may be thinner or finer than before.

External radiotherapy doesn’t make you radioactive. It’s perfectly safe for you to be around other people, including children, throughout your treatment.

We have a booklet called *Understanding radiotherapy*, which gives more information about this treatment and its side effects.
Possible long-term side effects

Some men may have side effects that don’t improve. Others may develop side effects many months or years after radiotherapy finishes. These are known as long-term or late effects.

We have a booklet called *Pelvic radiotherapy in men – possible late effects*, which tells you more about these effects and what can help.

**Erection problems**
Radiotherapy for prostate cancer can cause the inability to have an erection (erectile dysfunction – ED). Whether you develop erection problems or not will depend on your age and whether you are being treated with hormonal therapy as well. Erection problems may not happen straight after treatment. They sometimes develop over 2–5 years afterwards. Ask your oncologist if they can give you an idea of your likely risk of ED.

There are various treatments that can help if you develop ED – see pages 68–72.

**Infertility**
Radiotherapy to the prostate can cause permanent infertility. Some men find this very difficult to cope with. If you still want to father children, you may be able to store your sperm before treatment starts (see page 75).
Bowel or bladder problems
Some men may have bowel or bladder changes as a result of radiotherapy. The blood vessels in your bowel and bladder can become more fragile. This causes blood to appear in your urine or bowel motions. It can take many months or years to occur and can sometimes be a long-term effect. If you notice any bleeding, tell your doctor so that they can arrange tests and treatment if necessary.

Occasionally, your bowel movements may be more urgent after radiotherapy. Some men suffer from excessive wind. Very rarely, men have difficulty controlling their bowels (faecal incontinence). Tell your healthcare team if this happens. Although it may feel embarrassing to talk about, they can give you practical advice.

Often, radiotherapy can help improve problems with passing urine. But for a small number of men, it can lead to leakage of urine (urinary incontinence). This is due to damage to the nerves that control the bladder muscles. It’s unlikely to happen unless you’ve had an operation to remove part of the prostate gland (a transurethral resection of the prostate), or a prostatectomy as well as radiotherapy treatment. For more information about managing urinary incontinence, see page 73.

If this side effect occurs, tell your doctor. They can arrange for you to see a specialist continence nurse. You may also find it helpful to contact the Bladder and Bowel Foundation (see page 99 for details).
Lymphoedema
If radiotherapy has been given to the lymph nodes in the pelvic area as well as to the prostate, it can cause some swelling of the legs and genitals. This is known as lymphoedema.

We can send you a booklet about lymphoedema.

Advantages of external-beam radiotherapy

• It may lead to a cure for some men. For others it will help control the cancer for many years.

• Giving hormonal therapy before, during and/or after radiotherapy may improve the results.

Disadvantages of external-beam radiotherapy

• For a small number of men it can also cause long-term bowel problems, such as loose or more frequent bowel motions, bleeding from the back passage or an altered bowel pattern.

• A small number of men will develop urinary incontinence.

• Some men will develop erection problems and infertility.
Hormonal therapy

Hormonal therapy is usually given with radiotherapy to treat locally advanced prostate cancer, but it may be given on its own.

It may be given before radiotherapy to help shrink the tumour. This is known as **neo-adjuvant treatment**.

It may be given during or after radiotherapy to reduce the chance of the cancer coming back. This is known as **adjuvant treatment**.

Hormonal therapies can be given as injections or tablets.

**Injections**

Some drugs ‘switch off’ the production of male hormones by the testicles by reducing the levels of a hormone produced by the pituitary gland. They are known as leutenising hormone blockers or LHRH agonists. These include:

- goserelin (Zoladex®)
- leuprorelin (Prostap®)
- triptorelin (Decapeptyl®).

Goserelin is a small pellet which is injected under the skin of the tummy (abdomen). Leuprorelin and triptorelin are given as liquids which are injected under the skin or into a muscle. Injections are given either monthly or every three months.
Tablets

Other drugs work by attaching themselves to proteins (receptors) on the surface of the cancer cells. This blocks the testosterone from going into the cancer cells. These drugs are called anti-androgens.

Commonly used anti-androgens are:

- bicalutamide (Casodex®) – this is taken once daily
- flutamide (Drogenil®) – this is taken three times a day
- cyproterone acetate (Cyprostat®) – this is taken two or three times daily.

Anti-androgen tablets are usually given for one or two weeks before and after the first injection of a leutenising hormone blocker. This prevents tumour flare, which is when symptoms from the prostate cancer get worse after the first dose of treatment.

Duration of hormone treatment

Your doctor will advise how long you should have the hormonal therapy for. It may be stopped after the radiotherapy or continued for a period of 2–3 years, depending on the extent of the tumour at the start of treatment.

Some men may be treated with intermittent hormonal therapy, which means that the treatment is started and stopped depending on their PSA blood test result (see page 13). Intermittent therapy causes fewer side effects but you will need to have your PSA regularly monitored. It’s only suitable for some men.
Side effects

Erection problems
Most hormonal therapies cause erection difficulties (erectile dysfunction – ED) and loss of sexual desire (libido) for as long as the treatment is given and for some time after. Some drugs (goserelin and leuprorelin) completely stop erections during treatment. Others (such as bicalutamide) stop erections in most but not all men. Once hormone treatment is stopped, the problem may improve with time or treatment.

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

Your doctors may organise for you to have a DEXA scan (dual-energy x-ray absorptiometry scan) if you are due to start long-term hormone treatment. This scan allows doctors to monitor the bones for any areas of weakness or fractures. If your bones are thinning your doctor may advise you to take calcium and vitamin D tablets. You may also be asked to take bone-strengthening drugs called bisphosphonates or a drug called denosumab (Prolia®).

Our booklet Bone health has more information.

Hormonal effects
Most men experience hot flushes and sweating with hormonal therapy. Your doctor can give you medicines to help relieve this side effect while you’re having treatment. The flushes and sweats will gradually stop if treatment is stopped. We can send you more information about this.
Other effects
Hormonal treatment can also make you put on weight (often around the tummy area) and feel constantly tired. Some drugs (most commonly flutamide and bicalutamide) may also cause breast swelling and breast tenderness. There’s more information about managing breast swelling on page 75.

Different drugs have different side effects. It’s important to discuss these effects with your doctor or specialist nurse before you start treatment so that you know what to expect.

We have more information about individual hormonal therapies with details about how the drugs work and tips on coping with possible side effects. We also have information called Prostate cancer and hormonal symptoms, which we can send you.

Advantages of hormonal therapy

• It can slow or stop the growth of cancer cells for many years.

• It doesn’t involve surgery or radiation, so there’s little risk of bowel or bladder problems.

Disadvantages of hormonal therapy

• It won’t get rid of all the cancer cells if it’s the only treatment given.

• It can cause a range of side effects that include erection problems (erectile dysfunction – ED) and a lowered sex drive, hot flushes and breast swelling.
Removal of part of the testicles (subcapsular orchidectomy)

Occasionally an operation called a subcapsular orchidectomy (or radical orchidectomy) is done to remove the part of the testicles that produces testosterone. This reduces the level of the male hormone testosterone and helps control the prostate cancer and reduce symptoms. Both testicles are operated on (bilateral orchidectomy). It’s mostly used in men who can’t or don’t want to have the types of hormonal therapy mentioned on pages 36–39.

A subcapsular or radical orchidectomy is a simple operation. A small cut is made in the scrotum (the sac that holds the testicles), and the part of the testicles that produces testosterone is removed. After the operation the scrotum will be smaller than it was before. You usually have this operation as a day patient under a local or general anaesthetic.

After the operation, you’re likely to experience some pain, and some swelling and bruising of the scrotum. You will be given painkillers to ease any pain. You’ll also start to have side effects similar to those of hormonal therapy drugs, which include hot flushes and loss of erections (see page 38).

Some men find the idea of this operation distressing. You may find it helpful to talk through the procedure with your cancer specialist. They will give you more information about what it involves.
Advantages of having an orchidectomy

• It’s a simple operation that avoids the use of drugs and some of their side effects such as breast swelling and tenderness.

• It’s equally effective as other hormonal treatments.

Disadvantages of having an orchidectomy

• Some men find the idea of this operation difficult to cope with.

• There are some risks and side effects associated with surgery. Your specialist will give you more information about these.

• It can’t be reversed once the procedure has been carried out. It’s therefore not a good option for men who only need short-term hormonal therapy. If you are thinking about having a subcapsular orchidectomy talk to your doctor about this.
Watchful waiting

Some locally advanced prostate cancers grow very slowly and may never cause any symptoms. For this reason, some men decide with their specialists to wait and see whether the cancer is getting bigger (progressing) before starting any treatment. This is called watchful waiting and is a way of avoiding treatment for as long as possible. If treatment is given it is to control rather than cure the cancer.

You’ll be monitored, usually by your GP, to see if you have any new symptoms, such as difficulty passing urine or bone pain. You’ll also have regular blood tests to monitor your PSA levels and you may have digital rectal examinations.

If you develop symptoms, your GP will usually refer you back to the specialist at the hospital. You may be referred back if your PSA level rises. Your specialist will usually recommend hormonal therapy (see page 36) or possibly radiotherapy (see page 28) to control the cancer and improve its symptoms. If there’s no sign that the cancer is progressing or if it is only progressing slowly, it’s safe to continue with watchful waiting.

You can read more about the tests used during watchful waiting in our booklet Having tests for prostate cancer.
Advantages of watchful waiting

• It avoids the complications and side effects of hormonal therapy or radiotherapy.

Disadvantages of watchful waiting

• You may find it difficult to wait and see if your cancer progresses before starting any treatment.

• Some men will need treatment anyway if their cancer progresses.
Less common treatments

Brachytherapy

Brachytherapy is also called internal radiotherapy, implant therapy or seed implantation. The type of brachytherapy that may be used to treat locally advanced prostate cancer is known as high-dose rate (HDR) brachytherapy. It’s usually given with a course of external-beam radiotherapy (see pages 28–35).

HDR brachytherapy involves placing thin, metal or plastic tubes into the prostate gland. A radioactive material is then inserted into the tubes by a machine. The radioactive material is left in the tubes for a set period of time, and then withdrawn. After the treatment, the tubes are removed and no radioactive material is left in the prostate gland.

Planning

HDR brachytherapy is carried out in the operating theatre. You will usually have a general anaesthetic but some men have a local (spinal or epidural) anaesthetic. You may need to stay in hospital overnight.

Before the tubes are put in, your doctor will do a scan of your prostate gland to find out its exact size and position. The scan is carried out in the operating theatre. Your doctor passes an ultrasound probe into your rectum to take pictures of your prostate. The doctors use the pictures to decide the number of tubes that are needed and exactly where they should be placed.

Once the scan is done, your specialist will put the tubes that will be used to give you your brachytherapy into your prostate gland. A CT or MRI scan is taken so that the specialist can work out how much radiation to give you.
Treatment
A machine is used to insert the radioactive material into the tubes. A computer is used to monitor the length of time the radioactive material stays in place for, which is usually minutes. This may be done while you are asleep with a general anaesthetic or while you are awake.

Treatments vary. Some men need two or three treatments over a 24-hour period. If you need more than one treatment, the tubes are left in place between treatments. At the end of each treatment session the radioactive material is returned to the machine. You will need to stay in bed while the tubes remain in place. The tubes can be uncomfortable but you will be given painkillers if you need them. Once all the treatment has been completed the tubes are removed.

A catheter is sometimes inserted into the bladder to drain urine during the treatment(s). This is because the procedure may cause swelling of the prostate, which can lead to blockage of the urethra (the tube that drains urine from the bladder). The catheter will be removed before you go home.

After the treatment you have no radioactive material inside you, so it is perfectly safe for you to be with other people, including children.

Side effects of brachytherapy
Brachytherapy causes similar side effects to external radiotherapy (see pages 31–35).

It’s common to feel mild soreness, and to have some bruising and discoloration between the legs for a few days after the procedure. Your doctor can prescribe painkillers to relieve this.
Erection problems
Brachytherapy can cause erection problems some years after the treatment. The risk is the same with external radiotherapy (see page 33) but it may be higher if you’re having external-beam radiotherapy or hormonal therapy as well. Ask your specialist if they are able to give you an idea of your likely risk of erection problems. There’s more information about dealing with erection problems on pages 68–72.

Fertility
Brachytherapy may cause infertility in some men (see page 75). Your specialist will talk to you about this before your treatment.

Effects on the bowel
Brachytherapy may be less likely to affect the bowel than external radiotherapy. But if it is given with external radiotherapy the side effects will be the same.

Effects on the bladder
Brachytherapy may have some of the following side effects:

• You may notice some blood in your urine and semen for a few weeks. This is normal, but if it becomes severe or you have large clots, let your doctor know immediately. Drink plenty of water to help prevent blood clots and to flush the bladder.

• The procedure may cause some men to have difficulty passing urine due to swelling. You may have a catheter put in either during or after the procedure to help manage this. It will be removed when the tissues have healed. Sometimes difficulties passing urine may develop due to narrowing of the urethra. This can happen weeks or months after the procedure.

• Urine leakage may affect a small number of men. There’s more information about managing incontinence on page 73.
Some men find they have pain or discomfort when they pass urine, they need to pass urine more often, or they have a weaker urine stream. Drinking plenty of fluids and avoiding caffeine can help reduce these effects.

These problems are likely to be worse in the first few weeks after treatment. Usually they will then gradually improve.

Most men will be able to return to their normal activities 1–2 weeks after this treatment. But your recovery will take longer if you have external radiotherapy as well.

**Advantages of brachytherapy**

- Brachytherapy combined with external-beam radiotherapy may lead to a cure for some men with locally advanced prostate cancer. For others it can control the cancer for many years.

**Disadvantages of brachytherapy**

- It’s usually given in combination with external-beam radiotherapy, so it may not be possible to avoid frequent visits to hospital for treatment.

- It may cause erection problems, difficulty passing urine, urine incontinence and infertility.

- A general anaesthetic is required for the procedure, which has risks.
Surgery

This involves removing the prostate gland and is known as a **radical prostatectomy**. This operation is only suitable for a small number of men with locally advanced prostate cancer. This is because it may not be possible to remove all of the cancer cells that have spread outside the prostate gland. You can discuss with your specialist whether a prostatectomy would be suitable for you.

You will usually have hormonal therapy and/or external-beam radiotherapy after your prostatectomy.

Other types of surgery may sometimes be carried out to help with the symptoms caused by a locally advanced prostate cancer. An operation known as a **transurethral resection of the prostate (TURP)** may relieve symptoms such as difficulty passing urine. There’s more information about having a TURP on pages 55–57. Another operation known as a **subcapsular orchidectomy** may be carried out to remove part of the testicles. This reduces hormone levels and can help to control the cancer and symptoms. This operation is discussed in the hormonal therapy section on pages 40–41.

Your doctor will discuss the surgery with you before you have it. They will tell you what it involves, how successful it might be in treating your cancer or managing your symptoms and the possible side effects. Your doctor should also tell you about other treatments that may be more suitable for you.
Open radical prostatectomy

The surgery is carried out by a urologist (see page 24). In an open prostatectomy the urologist will remove the whole prostate gland, usually through a cut made in the tummy area (abdomen). Very occasionally the surgeon will remove the prostate gland through a cut made between the scrotum and the back passage (perineal prostatectomy). The nearby lymph nodes and the glands that help make semen (seminal vesicles) are also removed during the surgery.

After this operation you may be unable to have and maintain an erection (erectile dysfunction – ED). The operation will also affect your fertility. You’ll be unable to father children naturally. The operation can also cause problems with controlling your bladder (urinary incontinence). Sometimes it’s possible to do an operation called a nerve-sparing prostatectomy, which can reduce the risk of erection problems. However, this is often not possible for men with locally advanced prostate cancer.

As doctors can’t predict which men will be affected by these side effects, it’s important that you know about them before you have surgery.
Laparoscopic radical prostatectomy

With a laparoscopic prostatectomy your surgeon doesn’t need to make a large cut. Instead they take out your prostate gland using only four or five small cuts (about 1cm each) in your tummy (abdomen). This type of surgery is also known as keyhole surgery.

To start with, small cuts are made in the tummy and the tummy is filled with carbon dioxide gas. The surgeon then puts a small tube with a light and camera on the end (laparoscope) through one of the cuts. This shows a magnified image of the prostate gland on a video screen. Specially designed instruments are put through the small cuts. The surgeon uses these to cut away the prostate gland from surrounding tissues. The prostate gland is then removed through one of the small cuts.

Robotic-assisted laparoscopic radical prostatectomy

Sometimes, laparoscopic prostatectomy can be assisted by a machine. This is called a robotic-assisted laparoscopic prostatectomy. Instead of the surgeon holding the tube with the camera (laparoscope) and instruments, they are attached to robotic arms. The surgeon controls the robotic arms, which can move very delicately, steadily and precisely.

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

After your prostatectomy

After a prostatectomy you will have a drip (intravenous infusion) into a vein in your arm, and a tube (catheter) to drain urine from the bladder. If you’ve had an open prostatectomy you’ll have either an abdominal wound or a wound between your scrotum
and your anus. If you have had laparoscopic surgery you will have several small wounds. You may have a small tube in the wound to drain any excess fluid that is produced. This tube is usually removed after a few days.

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

You will probably be ready to go home 3–7 days after open surgery or 1–2 days after laparoscopic surgery.

Your catheter will usually stay in place for a short while after you go home. This allows urine to drain freely while the urethra heals and any swelling goes down. It can be removed at the outpatient clinic 1–3 weeks after the operation. A district nurse can visit you at home if needed to make sure your catheter is working well. If you have any problems, contact your doctor, specialist nurse or the ward where you had your surgery as soon as possible.

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

Before you leave hospital you’ll be given an outpatient appointment for your post-operative check-up. This is a good time to discuss any problems you may have.

Most men return to their normal activities 4–12 weeks after surgery for prostate cancer. It will depend on the type of surgery you have had (open or laparoscopic) and your work or home circumstances.
Side effects of a radical prostatectomy

Problems getting an erection
Surgery to the prostate can cause problems getting or keeping an erection (erectile dysfunction – ED). This is caused by damage to the nerves. Nerve-sparing techniques have reduced the risk of these problems, but often the need to remove all of the cancer cells makes it impossible to avoid nerve damage.

Studies have looked at how many men might have problems getting an erection following nerve-sparing surgery. The numbers tend to vary as it depends on factors such as whether or not you had erection problems before treatment, your age, and whether the surgeon was able to spare some or all of the nerves. You can ask your surgeon to give you an idea of your likely risk of ED.

Some men who have surgery on its own may find that their ability to have an erection gradually returns. It may take as long as a year or two for this to happen. It’s less likely to return in men who have treatment after surgery, such as hormonal therapy (see pages 36–41) or radiotherapy (see pages 28–35 and 44–47). Ways to cope with erection problems are discussed on pages 68–72.

Inability to father children (infertility)
The prostate gland produces semen, which is normally mixed with sperm from the testicles. Removing the prostate gland makes it impossible for men to ejaculate. Although there is still sperm, it can’t get out of the body. This causes infertility. If you want children after your treatment, it may be possible to store sperm before your surgery (see page 75).

It’s still possible for men who have had their prostate gland removed to have an orgasm, but there will be no ejaculation. This is known as a dry ejaculation. A dry ejaculation may cause some discomfort at first but this usually improves with time.
Problems controlling your bladder (urinary incontinence)
This is a less common side effect. Most men have some incontinence when their catheter is first removed. This usually improves with time and pelvic floor exercises. A small number of men may have some ongoing incontinence, which may be worse when bending, coughing, sneezing or doing exercise. It’s very rare to be completely incontinent. Talk to your doctor or nurse if you have ongoing incontinence. They can refer you to a continence team who can give you advice about coping with this problem.

Another less common effect of surgery is scarring of the bladder or urethra. The urethra is the tube that runs from the bladder to the tip of the penis. It takes urine away from the bladder. Scar tissue can make passing urine difficult. It can be treated with minor surgery.

Advantages of an open prostatectomy

- It may cure the cancer.
- It may prolong the life of men with fast-growing cancers.

Disadvantages of an open prostatectomy

- It is only suitable for a small number of men with locally advanced prostate cancer
- Some men may require radiotherapy after surgery if there’s a possibility that cancer cells have been left behind.
- For some men, cancer cells may come back immediately or some time after the operation. If this happens, radiotherapy or hormonal therapy may be given.
Advantages of laparoscopic prostatectomy

- Laparoscopic/robotic surgery is as successful at treating prostate cancer as open surgery.
- Most men who have laparoscopic surgery spend less time in hospital and recover more quickly from their operation compared to men having an open prostatectomy.

Disadvantages of laparoscopic prostatectomy

- Because laparoscopic surgery, particularly robotic surgery, hasn’t been used for as long as open prostatectomy, we don’t know if it’s better at reducing long-term side effects (ED and incontinence) compared to open prostatectomy.

Transurethral resection of the prostate (TURP)

A TURP is carried out if cancer is blocking the urethra (the tube that drains urine from the bladder) and needs to be removed. It helps relieve problems with passing urine.

During the procedure, a 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 to remove the blockage.

This can be done under a general anaesthetic while you’re asleep or you may have a local anaesthetic with an epidural.
If you have an epidural, the lower body is temporarily numbed with an injection of anaesthetic into the spine. Even though you are awake, you won’t feel anything.

A TURP can also be carried out using a special laser. This is only done in some specialist 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 get out of bed and will probably be able to walk around the morning after your operation.

You will usually have a drip that gives fluid into your vein. This will be taken out as soon as you’re drinking normally.

You’ll also have a tube (catheter) to drain fluid from your bladder into a collecting bag. It’s normal at this stage for your urine to contain blood. To stop blood clots blocking the catheter, bladder irrigation may be used. This is when fluid is passed into the bladder and drained out through the catheter. The blood will gradually clear from your urine and the catheter can then be taken out. At first, you may find it difficult to pass urine without the catheter, but this should improve. Some men find that they have some urinary incontinence following this procedure, but this usually improves within a few weeks.

Most men are able to go home after three or four days. Occasionally, you may need to keep the catheter in for a while after you go home due to swelling caused by the surgery. 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.
If you go home with a catheter you may experience some bladder spasms due to your catheter irritating your bladder. The spasms may cause your urine to bypass your catheter so that you leak urine. These spasms are normal and not dangerous to you, but if they last a long time and are frequent, tell your doctor or nurse.

You may have pain and discomfort for a few days after your operation. You will be given painkillers, which are usually very effective. If you continue to feel pain, let your doctor or nurse know so that a more effective painkiller can be found.

Following a TURP it’s common for men to experience retrograde ejaculation. This means that during ejaculation semen goes backward into the bladder instead of through the urethra in the normal way. Your urine may look cloudy after sex because there is semen in the bladder, but this is harmless.

Occasionally, TURP can cause some long-term difficulties with passing urine. Some men may also find that they have problems getting an erection after having a TURP.

**Advantages of a TURP**

- It can help to relieve problems with passing urine.

**Disadvantages of a TURP**

- There is a small risk of urinary incontinence and some men have problems getting an erection after a TURP.
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, hormonal therapies 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.

Our booklet *Understanding cancer research trials (clinical trials)* describes clinical trials in more detail.

**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.

**Prostate cancer research trials**

Some prostate cancer treatments are given as part of a clinical trial because doctors are still trying to find out more about their side effects and how effective they are. Your doctor will be able to tell you about any clinical trials that may be suitable for you. Our website [macmillan.org.uk](http://macmillan.org.uk) has information about current clinical trial databases.
AFTER TREATMENT

Follow-up  62
Beginning to recover  63
Dealing with treatment side effects  68
Follow-up

After your treatment finishes, you’ll have regular check-ups, usually involving a PSA test (see page 13).

At first you may be seen by your cancer specialist at the hospital. You may then be followed up by your GP, who will arrange for you to have regular PSA tests. Speak to your cancer specialist about how you will be followed up after treatment, and who you can discuss any problems with.

Many men find they get anxious for a while before the appointments. This is natural. It may help to get support from family, friends or one of the organisations listed on pages 99–104 during this time.

After treatment, some men are cured of locally advanced prostate cancer. Others may need ongoing treatment because their cancer comes back. If your cancer comes back your doctor will discuss treatment with you.

‘I’ve got my head around the cancer and everything now. If something comes back, we’ll cross that bridge when we come to it, and we’ll deal with it.’

Peter
Beginning to recover

Cancer treatment can be very hard on your body and it may be some time before you’re feeling fit and well again. Some men have side effects that gradually improve over time, while others may have ongoing or delayed side effects (see pages 68–75).

Not all men experience specific side effects, but they may have a range of other effects, such as trouble sleeping, or feeling weaker and more tired than usual. Some may have lost or gained weight, or have stiff muscles or joints.

Living a healthy lifestyle can help your body recover more quickly. Healthy living will also help to reduce the risk of other illnesses, such as heart disease and strokes.

Lifestyle changes

Some men want to make changes to their lifestyle after their prostate cancer experience. You can either choose to make just a few changes or completely change the way you live.

A healthy lifestyle can include having a well-balanced diet, getting some exercise, reducing stress, and being involved in your healthcare. You will need to take any side effects of treatment into consideration when planning changes to your diet and exercise. Try not to do too much too soon.

Adopting a healthy lifestyle doesn’t have to be difficult or expensive.
A healthy diet
A well-balanced diet should include:

- plenty of fresh fruit and vegetables – aim to eat at least five portions a day
- foods high in fibre, such as beans and cereals
- plenty of water or other non-alcoholic drinks.

You should also try to reduce your intake of:

- red meat, processed meat and animal fats
- alcohol
- salted, pickled and smoked foods.

Smoking
If you smoke, you should also try to give up.

There are some useful tips in our booklet Giving up smoking.

Physical activity
Exercise doesn’t have to be very strenuous. Start gently and build up the amount of physical activity you do. Whatever your age or physical health there will be some kind of exercise you can try, such as walking, hiking, cycling or swimming. Activities like gardening, dancing and playing sport are also very effective.

Our booklet Physical activity and cancer treatment has more ideas.
Reduce stress
There are lots of ways to reduce stress. Try doing things you enjoy and that make you laugh. Some people find it relaxing to meditate or to pray, or to start a new pastime or an evening class. You may find it helpful to write a journal or online blog.

Be involved in your healthcare
This means taking your medicines as prescribed, going for follow-up appointments and being aware of symptoms that might mean your cancer has come back.

If you’re thinking about making some major changes to your lifestyle, discuss your plans with your doctor or specialist nurse.

Get help and support
Different people can help you during and after your treatment.

If you need practical help at home during or after treatment, a nurse or hospital social worker may be able to arrange this. A social worker or benefits adviser can tell you about benefits you may be able to claim and help with other costs. If you need help with a catheter, the district nurses can visit you at home.

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, nurse 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.

Self-help or support groups offer a chance to talk to other men who understand what you’re going through. You can call us or visit our website for information about support groups in the UK.
Many people get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share what you’ve been through, to ask questions, and to get and give advice based on your prostate cancer experience.

Our online community (macmillan.org.uk/community) is a social networking site where you can talk to people in our chat rooms, write blogs, make friends and join support groups.
Dealing with treatment side effects

Unfortunately, treatment for prostate cancer can cause unpleasant and distressing side effects – both short- and long-term.

Sexual problems/erection difficulties

Any type of treatment can make you less interested in sex. This is known as loss of libido and is common to many illnesses, not just cancer. Erection difficulties (erectile dysfunction – ED) are a fairly common side effect of prostate cancer treatment. However, the problems may not be permanent and can sometimes be caused by anxiety rather than the treatment itself.

Many men find it difficult to talk about personal subjects such as erection problems, particularly with their doctor or other healthcare staff. Some men also find it difficult to talk to their partner, if they have one, due to fear of rejection – but these fears are often unfounded. Sexual relationships are built on many things, such as love, trust and common experiences. It can help to talk to your partner about your fears and worries.

You may find it helpful to read our leaflet Cancer, you and your partner.

If you find the effect on your sex life difficult to deal with, discuss this with your doctor. Although you may worry that it will be embarrassing, doctors who deal with prostate cancer are used to talking about these issues and can give you advice.
There are practical ways to help overcome ED and your doctor can give you information about these. Most hospitals also have specialist nurses who can discuss the issues with you.

‘Once I was diagnosed with prostate cancer and was on hormone drugs, the first thing I noticed was that my sex life was being affected due to erectile dysfunction. I was a little disturbed about that, but I found I could talk it through with my partner.’

Percy

**Tablets**

There are a number of tablets you can take to help you get or maintain an erection. These can be prescribed by your GP. They will give you an erection but won’t necessarily increase your feelings of arousal. All have similar benefits and risks.

- Sildenafil (Viagra®) tablets produce an erection by increasing the blood supply to the penis. It’s usually taken 30–60 minutes before sex, on an empty stomach, and following direct sexual stimulation, an erection can occur. Viagra should be prescribed by your GP. It may not be recommended for you if you have certain heart problems and/or are taking certain drugs, such as nitrates. It can cause side effects for some people, including heartburn, headaches, dizziness and visual changes.
• Vardenafil (Levitra®) tablets are similar to sildenafil. They normally work within 25–60 minutes. The most common side effects are headaches and flushing of the face.

• Tadalafil (Cialis®) can help produce an erection. It works by increasing the effects of one of the chemicals produced in the body during sexual arousal. It shouldn’t be taken by people who are taking certain heart medicines. Your doctor can prescribe you tadalafil to take once a day or just when needed. Your doctor will discuss the differences between these options with you. You take the ‘as-needed’ preparation 30 minutes to two hours before sexual activity. The medicine remains active for around 36 hours. The once-daily medicine takes around 5–7 days to build up in the body. Once started, you need to take it every day for it to work.

These tablets require sexual stimulation in order to achieve an erection.

Injections
Some men may be able to use injections of a drug called alprostadil (Caverject®, Viridal®). A small needle is used to inject these drugs directly into the shaft of the penis. The drugs restrict blood flow and trap blood in the penis. They cause an instant erection. Some experimentation is often needed at first to get the dose right. These injections are only recommended for use once a week.

Pellets
Pellets of alprostadil (MUSE®) can also be inserted into the penis. An applicator is used to insert the pellet which melts into the urethra. After some rubbing to distribute the pellet into the nearby tissues, it produces an erection. Some men find that the pellet is uncomfortable at first.
Alprostadil is prescribed by your GP. The first dose of the injection or pellet is given by a healthcare professional. Talk to your specialist doctor or nurse if you would like to know more about these treatments.

A possible but rare side effect of these injections, pellets and to a lesser extent the tablets, is that occasionally the erection lasts for several hours. This is known as priapism. It can damage the tissues of the penis. If your erection lasts longer than two hours, get medical help as soon as possible. The person who prescribes these medicines will explain what the risks, and treatments, for priapism are.

**Vacuum pumps**

These can also be used to produce an erection. They are sometimes called vacuum constriction devices.

The pump is a device with a hollow tube that you put your penis into. The pump makes the penis fill with blood by creating a vacuum. A rubber ring is then put around the base of the penis to give an erection. The erection can be maintained for about 30 minutes.

Once you have finished having sex, the ring is taken off and the blood flows normally again. The advantage of this device is that it doesn’t involve inserting anything into the penis or taking any drugs. It’s particularly helpful for people who aren’t able to take other medicines. But it can take a few tries to get used to it.

Your partner may find your penis is slightly colder than usual.

The ring should only be worn for half an hour at a time, but it can be used as many times as you want, as long as you allow half an hour between each use.
Penile implants
These are sometimes used after all other methods have been tried. A penile implant is inserted during an operation. There are two main types. The first type uses semi-rigid rods that keep the penis fairly rigid all the time, but allow it to be bent down when an erection isn’t needed. The second type is an inflatable device that, when activated, causes an erection. Your doctor can discuss penile implants with you.

If you think any of these options might be useful to you, your doctor or nurse can give more information or you can contact the organisations on pages 99–100.

Most men who have erection problems after a prostatectomy or radiotherapy will probably benefit from these treatments, but everyone is different. Specialist advice and counselling can also be useful. You can ask your doctor to refer you for this help, or you can contact one of the organisations on pages 103–104.

Our booklet Sexuality and cancer – information for men discusses all of these methods in detail. It also talks about the effect that sexual problems may have on your relationship.
Urinary incontinence

Losing control of your bladder may be caused by the cancer itself, by surgery or, rarely, by radiotherapy. A lot of progress has been made in dealing with incontinence, and there are several different ways of coping with the problem. Discuss any concerns you have with your doctor or nurse. Some hospitals have staff who are specially trained to give advice about incontinence. The Bladder and Bowel Foundation (see page 99) also has useful information.

Just Can’t Wait toilet card
If you need to go to the toilet more often, or feel that you can’t wait when you do want to go, you can get a card to show to staff in shops, restaurants and pubs. The Just Can’t Wait toilet card allows you to use their toilets, without them asking awkward questions. You can get the cards from the Bladder and Bowel Foundation for a small fee.

‘After my treatment, I had to come to terms with urinary incontinence. It’s been brought under control now. I’m not completely “watertight”, but it’s nothing I can’t live with.’

Duncan
Infertility

Most treatments for prostate cancer are likely to cause infertility, which means you will no longer be able to father a child naturally. This may be very distressing if you want to have children.

Your cancer specialist can talk to you about this before you start treatment, and you may wish to discuss the issue with your partner if you have one. It’s usually possible to store sperm before treatment starts. The sperm may then be used later as part of fertility treatment.

We have information about ways of preserving fertility in our leaflet Cancer treatment and fertility – information for men.

Breast swelling

Some hormonal therapies may cause breast swelling. Ask your doctor whether this is likely to happen to you. They may advise a short course of low-dose radiotherapy to your breast tissue before you start treatment. This may prevent any breast swelling and causes very few, if any, side effects.

If you are taking bicalutamide (see page 37) another option is to also take a hormonal drug called tamoxifen to prevent breast swelling.
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 anti-depressant drug.

Our booklet *How are you feeling? The emotional effects of cancer* discusses the feelings you may have in more detail, and has suggestions for coping with them.
Your feelings and relationships

Your relationships

Your cancer experience may have improved your relationships with people close to you. Support from family and friends may have helped you cope. But cancer is stressful and can affect your relationships.

Your partner

Some couples become closer when one partner has cancer. However, cancer can put a lot of strain on a relationship. Problems can develop, even between couples who have been together for a long time. If a relationship was already difficult, the stress of a major illness may make things worse.

Even couples who are close may not always know how their partner is feeling. Talking openly about your feelings and listening to each other can help you understand each other.

Our booklets Cancer, you and your partner and Sexuality and cancer – information for men have more information that may help.

Family and friends

Your family and friends may not always understand if you are not feeling positive. They may not know how much your treatment is affecting your life. Talking about how you feel will help them give you the support you need.

Our booklet Talking about your cancer has some useful tips.
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 Lost for words – how to talk to someone with 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.

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

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

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

Teenagers

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

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

Our booklet Talking to children and teenagers when an adult has cancer includes discussion about sensitive topics. There’s also a video on our website that may help, at macmillan.org.uk/talkingtochildren.
Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- contributory – you can get this if you have made enough national insurance contributions
- income-related – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called **Universal Credit** has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

**Personal Independence Payment (PIP)** is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called Disability Living Allowance (DLA) in England, Scotland and Wales.
Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don’t need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the ‘special rules’. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carers Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don’t qualify for it, you can apply for Carer’s Credit. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it’s a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on 0808 808 00 00. We’ve just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at gov.uk (England, Scotland and Wales) and nidirect.gov.uk (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 105) or Citizens Advice (see page 104). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on 0800 220 674.
Our booklet *Help with the cost of cancer* has more detailed information. You might also find our video at macmillan.org.uk/gettingfinancialhelp useful.

**Insurance**

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 104–106.

Our booklets *Insurance* and *Getting travel insurance* may also be helpful.
Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It’s important to do what’s right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It’s important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

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

All of our information is also available online at macmillan.org.uk/cancerinformation 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
• 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. No one should face cancer alone.

Talk to us

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

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

• help with any medical questions you have about your cancer or treatment

• help you access benefits and give you financial advice

• 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 advice
Our financial guidance team can give you advice 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

Macmillan’s My Organiser app
This 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 Foundation**
SATRA Innovation Park, Rockingham Road, Kettering NN16 9JH
**Helpline** 0845 345 0165
**Email** info@bladderandbowelfoundation.org
**www.bladderandbowelfoundation.org**
Provides information and advice on symptoms and conditions related to the bladder and bowel, including incontinence.

**Orchid Cancer Appeal**
St Bartholomew’s Hospital, London, EC1A 7BE
**Tel** 0203 465 5766 (Mon–Fri, 9am–5.30pm)
**Email** info@orchid-cancer.org.uk
**www.orchid-cancer.org.uk**
Funds research into men’s cancers, their diagnosis, prevention and treatment.

Has free information leaflets and fact sheets, and runs an enquiry service supported by Orchid Male Cancer Information Nurses.

**Prostate Cancer Support Scotland**
GF, 6 Hill Street, Edinburgh EH2 3JZ
**Tel** 0131 603 8660
**Email** info@prostatescotland.org.uk
**www.prostatescotland.org.uk**
Scottish charity set up to provide information, advice and help on prostate health and diseases of the prostate. You can watch videos online and download free leaflets and booklets.
Prostate Cancer UK
4th Floor, Counting House,
53 Tooley Street,
London SE1 2QN
Helpline 0800 074 8383
Email info@prostatecanceruk.org
www.prostatecanceruk.org
Fights to help more men survive prostate cancer and enjoy a better quality of life. Provides support and information.

Tackle Prostate Cancer
16 Kirby Street,
London EC1N 8TS
Helpline 0845 601 0766
Email helpline@tackleprostate.org
www.tackleprostate.org
A campaign run by the Prostate Cancer Support Federation that raises awareness of prostate cancer, encourages early detection and seeks to ensure that men always get the best treatment whatever the stage of their disease.

General cancer support organisations

Cancer Black Care
79 Acton Lane,
London NW10 8UT
Tel 020 8961 4151
Email info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

Cancer Focus Northern Ireland
40–44 Eglantine Avenue,
Belfast BT9 6DX
Tel 0800 783 3339 (Mon–Fri, 9am–1pm)
Email hello@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Research UK
Angel Building,
407 St John Street,
London EC1V 4AD
www.cancerhelp.org.uk
**Further information**

**Tel** 0300 123 1022
Has patient information on all types of cancer and has a clinical trials database.

**Cancer Support Scotland**
The Calman Centre,
75 Shelley Road,
Glasgow G12 0ZE
**Tel** 0800 652 4531
**Email** infocancersupportscotland.org
**www.cancersupportscotland.org**
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

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

**Maggie’s Centres**
2nd Floor, Palace Wharf,
Rainville Road,
London W6 9HN
**Tel** 0300 123 1801
**Email** enquiries@maggiescentres.org
**www.maggiescentres.org**
Provides information about cancer, benefits advice, and emotional or psychological support.

**Penny Brohn Cancer Care**
Chapel Pill Lane,
Pill, Bristol BS20 0HH
**Tel** 01275 371 100
(Mon–Fri, 9.30am–5pm)
**Email** helpline@pennybrohn.org
**www.pennybrohncancercare.org**
Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

**Riprap**
Att Pauline Hutchinson,
University of Sheffield,
Sykes House Office,
St Luke’s Hospice,
Little Common Lane,
Sheffield S11 9NE
**www.riprap.org.uk**
Developed especially for teenagers who have a parent with cancer.
Tenovus
Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD
Tel 0808 808 1010
(Mon–Sun, 8am–8pm)
www.tenovus.org.uk
Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as a free helpline, an ‘Ask the nurse’ service on the website and benefits advice.

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@healthtalkonline.org
www.healthtalk.org
www.youthhealthtalk.org
(site for young people)
Has information about cancer, and videos and audio clips of people’s experiences.

National Cancer Institute – National Institute of Health – USA
www.cancer.gov
Gives information on cancer and treatments.

NHS Choices
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
www.nhsinform.co.uk
NHS health information site for Scotland.

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

British Association for Counselling and Psychotherapy (BACP)
BACP House,
15 St John’s Business Park,
Lutterworth,
Leicestershire LE17 4HB
Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at itsgoodtotalk.org.uk

College of Sexual and Relationship Therapists
PO Box 13686,
London SW20 9ZH
Tel 020 8543 2707
Email info@cosrt.org.uk
www.cosrt.org.uk
Leading UK membership organisation for therapists specialising in sexual and relationship issues. Website has information about sex and relationships, and a directory of therapists.

Relate
Premier House,
Carolina Court, Lakeside,
Doncaster DN4 5RA
Tel 0300 100 1234
www.relate.org.uk
Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face to face, by phone and online.

Samaritans
Freepost RSRB-KKBY-CYJK,
Chris, PO Box 9090,
Stirling FK8 2SA
Tel 08457 90 90 90
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.
Sexual Advice Association
Suite 301, Emblem House, London Bridge Hospital, 27 Tooley Street, London SE1 2PR
Tel 0207 486 7262
Email info@sexualadviceassociation.co.uk
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.

UK Council for Psychotherapy (UKCP)
2nd Floor, Edward House, 2 Wakley Street, London EC1V 7LT
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.

Financial or legal advice and information

Benefit Enquiry Line
Northern Ireland
Tel 0800 220 674
(Mon–Wed and Fri, 9am–5pm, Thu, 10am–5pm)
Textphone 0800 243 787
www.nidirect.gov.uk/money-tax-and-bfits
Provides information and advice about disability benefits and carers’ benefits.

Citizens Advice
Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

England and Wales
www.citizensadvice.org.uk

Scotland
www.cas.org.uk

Northern Ireland
www.citizensadvice.co.uk

You can also find advice online in a range of languages at adviceguide.org.uk
Civil Legal Advice
Tel 0845 345 43 45  
(Mon–Fri, 9am–8pm,
Sat, 9am–12.30pm)
Minicom 0345 609 6677
www.gov.uk/civil-legal-advice
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English isn’t your first language.

Department for Work and Pensions (DWP)
Disability Living Allowance Helpline 0345 712 3456
Textphone 0345 722 4433
Personal Independence Payment Helpline 0345 850 3322
Textphone 0345 601 6677
Carer’s Allowance Unit 0345 608 4321
Textphone 0345 604 5312
www.gov.uk/browse/benefits
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK
www.gov.uk
Has comprehensive information about social security benefits and public services.

Law Society
113 Chancery Lane, London WC2A 1PL
Tel 020 7242 1222
www.lawsociety.org.uk
Represents solicitors in England and Wales, and can provide details of local solicitors. You can submit enquiries to them through their website.

Law Society of Scotland
26 Drumsheugh Gardens, Edinburgh EH3 7YR
Tel 0131 226 7411
Email lawscot@lawscot.org.uk
www.lawscot.org.uk

Law Society of Northern Ireland
96 Victoria Street, Belfast BT1 3GN
Tel 028 9023 1614
www.lawsoc-ni.org
You can submit enquiries to them through their website.
Money Advice Scotland
Tel 0141 572 0237
www.moneyadvice.scotland.org.uk

Money Advice Service
Tel 0300 500 5000
(Mon–Fri, 8am–8pm, Sat, 9am–1pm)
Typetalk
18001 0300 500 5000
www.moneyadvice.service.org.uk
Runs a free financial health check service and gives advice about all types of financial matters. Has an online chat service for instant money advice.

National Debtline
(England, Scotland and Wales)
Tricorn House, 51–53 Hagley Road, Edgbaston, Birmingham B16 8TP
Tel 0808 808 4000
(Mon–Fri, 9am–9pm, Sat, 9.30am–1pm)
www.nationaldebtline.co.uk
A national helpline for people with debt problems. The service is free, confidential and independent.

Personal Finance Society – ‘Find an Adviser’ service
www.findanadviser.org
Use the website to find qualified financial advisers in your area.

Turn2Us
Unit 9, Cefn Coed Parc, Nantgarw, Cardiff CF15 7QQ
Tel 0808 802 2000
(Mon–Fri, 9am–8pm)
Email info@turn2us.org.uk
www.turn2us.org.uk
Provides an online service to help the millions of people in financial need in the UK. Use its website free to access information about the benefits and grants available to you from both statutory and voluntary organisations. You can apply for support directly from the website.

Unbiased.co.uk
Email contact@unbiased.co.uk
www.unbiased.co.uk
On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.
Support for older people

Age UK
Tavis House,
1–6 Tavistock Square,
London, WC1H 9NA
Tel (England and Wales) 0800 169 6565
Tel (Scotland) 0845 125 9732
Tel (Northern Ireland) 0808 808 7575
(Daily, 8am–7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for carers

Carers Trust (Princess Royal Trust for Carers in Scotland)
32–36 Loman Street,
London SE1 0EH
Tel (England) 0844 800 4361

Carers UK
Tel (England, Scotland, Wales) 0808 808 7777
Tel (Northern Ireland) 028 9043 9843
(Wed–Thu, 10am–12pm and 2–4pm)
Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Tel (Scotland) 0300 123 2008
Tel (Wales) 0292 009 0087
Email info@carers.org
www.carers.org and www.youngcarers.net
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.

You can search for more organisations on our website at macmillan.org.uk/organisations, or call us on 0808 808 00 00.
YOUR NOTES AND QUESTIONS
Disclaimer

We make every effort to ensure that the information we provide is accurate but it should not be relied upon to reflect the current state of medical research, which is constantly changing. If you are concerned about your health, you should consult a doctor. Macmillan cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third-party information, such as information on websites to which we link. We feature real-life stories in all of our articles.

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 Editor, Dr Lisa Pickering, Consultant Medical Oncologist; and our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Mark Beresford, Consultant Clinical Oncologist; Jane Booker, Macmillan Urology Clinical Nurse Specialist; Mr Simon Brewster, Consultant Urological Surgeon; Sharon Clovis, Prostate Clinical Nurse Specialist; and Dr Duncan McLaren, Clinical Oncologist.

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

Sources

We’ve listed a sample of the sources used in this publication below. If you’d like further information about the sources we use, please contact us at bookletfeedback@macmillan.org.uk


Can you do something to help?

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

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

**5 WAYS YOU CAN HELP SOMEONE WITH CANCER**

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

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

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

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

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

Call us to find out more
0300 1000 200
macmillan.org.uk/getinvolved
Please fill in your personal details

Mr/Mrs/Miss/Other
Name
Surname
Address
Postcode
Phone
Email

Please accept my gift of £
(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expire 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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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

If you’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
Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That’s who we are.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you’re entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community supporting you online, any time. The fundraisers who make it all possible.

You don’t have to face cancer alone. We can give you the strength to get through it. We are Macmillan Cancer Support.

Questions about living with cancer? Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm) Alternatively, visit macmillan.org.uk
