UNDERSTANDING EARLY (LOCALISED) PROSTATE CANCER
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About this booklet

This booklet is for men who have been diagnosed with early (localised) prostate cancer. This is when cancer is only in the prostate gland and has not spread into the surrounding tissues or to other parts of the body.

We hope it 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, which we hope you’ll find useful.

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.

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

Turn to pages 121–130 for some useful addresses and websites, and pages 131–133 to write down questions for your doctor or nurse.
In this booklet we’ve included quotes from people with prostate cancer, which you might find helpful. Some are from healthtalkonline.org Others are from people who have chosen to share their experience with us by becoming a Cancer Voice. To find out more, visit macmillan.org.uk/cancervoices

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 dies.

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 page 10).
When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.
The prostate 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 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 depend 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 the prostate are collections of lymph nodes. These are small glands, each about the size of a baked bean. They form part of the lymphatic system (see page 10).
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 cancer cells from the prostate gland can spread to nearby lymph nodes or more distant lymph nodes. Early (localised) prostate cancers have not spread to the 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 a proportion of men, prostate cancer can grow more quickly and in some cases may spread to other parts of the body, particularly the bones.
Understanding early (localised) prostate cancer

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 high 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. Men under 50 have a very low risk of prostate cancer. The risk increases as they get older. Approximately 75 in 100 prostate cancers (75%) 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 had only one relative who developed prostate cancer at an older age, your risk is likely to be similar to that of 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 who developed prostate cancer at or under the age of 60 (a first-degree relative is a father, brother or son)

• 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, nephew).
'Both my father and my paternal grandfather suffered from prostate cancer. MY GP was monitoring me closely. When I was diagnosed with the condition, it was not entirely unexpected, but devastating nonetheless.'

Robert

Experts think that 5–15 in 100 prostate cancers (5–15%) are linked to inherited gene changes that increase the risk of developing it.

There isn’t one specific ‘prostate cancer gene’ that can explain most of the cases of hereditary prostate cancer. It is thought that it may be linked to variations in several genes. 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.
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 products (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 cancer and other illnesses.
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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 gives information about 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** 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 information about the nodes that were examined:

- **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.

If you have early prostate cancer, you will most likely see NX or N0 because the cancer is just in the prostate.

**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 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.

If you have early prostate cancer, you will most likely see M0 because the cancer is just in the prostate.
You can talk to your doctors about your TNM staging. They will be able to explain it to you. Our cancer support specialists can also tell you more about TNM staging. You can call them on 0808 808 00 00.

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

**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.

All your biopsy samples are graded. The most common grade in the samples and the highest grade of the other samples are added together. This gives a Gleason score that ranges between 6–10.

Low-grade cancers have a Gleason score of 6. They are usually slow-growing and less likely to spread. High-grade cancers have a Gleason score of 8–10. They are more likely to grow quickly and to spread.
Understanding early (localised) prostate cancer

Prostate cancer risk groups

Early (localised) prostate cancer is divided into risk groups. These help doctors decide on the best treatment options. There are three risk groups:

• **Low risk** means the prostate cancer is unlikely to grow for many years.

• **Intermediate risk** means the prostate cancer is unlikely to grow for a few years.

• **High risk** means the prostate cancer is more likely to grow or spread in a few years.

To work out your risk group your doctor will look at your Gleason score, your PSA level and the stage of your cancer. If you would like more information about your risk group, ask your doctor.
Prostate cancer
Treatment overview

This section tells you about the different treatments for early 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 about that treatment.

Treatment options

The main treatment options for early prostate cancer include active surveillance, watchful waiting, surgery, radiotherapy and hormonal therapy.

Active surveillance – (see pages 35–37)
This is when your doctors monitor your cancer and only give you treatment – usually radiotherapy or surgery – to cure your cancer if your cancer starts to progress. If your cancer doesn’t progress, you will avoid treatment and its side effects.

You may be advised to have this if you have a slow-growing prostate cancer (low-risk cancer – see page 22) or you have an intermediate risk cancer but wish to avoid having surgery or radiotherapy straight away.

Watchful waiting (watch and wait) – (see pages 38–39)
This is also when your doctors monitor your cancer. It’s a way of avoiding treatment for as long as possible. If your cancer starts to progress or you develop symptoms, you will be offered hormonal therapy to control it.
You may be advised to have watchful waiting if:

- you are an older man with no symptoms from your cancer
- you have medical problems that mean you are not fit enough to have radiotherapy or surgery.

Some elderly men who have watchful waiting may never need any active treatment because their cancer is very slow-growing and it is unlikely to affect their natural life span.

**Surgery – (see pages 40–48)**
This involves removing the whole prostate gland. Men are offered surgery if they have a faster-growing cancer (intermediate- or high-risk cancer – see page 22) and they are fit enough to have a major operation. The aim of treatment is to cure the cancer.

**Radiotherapy – (see pages 49–70)**
This uses high-energy x-rays to destroy the cancer cells, while doing as little harm as possible to normal cells. It is commonly given as external beam radiotherapy but it can also be given internally. Internal radiotherapy is known as brachytherapy.

Radiotherapy is commonly offered to men who have faster-growing cancers (intermediate- or high-risk cancers – see page 22) and who are fit enough to have the treatment. The aim of treatment is to cure the cancer.

Radiotherapy is equally effective as surgery so you may be asked to choose which treatment you want.
Hormonal therapy – (see pages 71–75)
Hormones control the growth and activity of normal cells. Prostate cancer depends on the hormone testosterone, which is produced in the testicles, in order to grow. Hormonal therapies reduce the amount of testosterone in the body. They can be given as injections or tablets.

Hormonal therapy may be given before, during or after radiotherapy to make the treatment more effective. It may also be given on its own as a treatment for older men or men who aren’t well enough for other treatments.

Other treatments
Other treatments, such as cryotherapy (this is also known as cryosurgery) or high-intensity focused ultrasound (HIFU) treatment may be offered to some men. These treatments are still being researched to see how effective they are so they are usually given as part of a trial (see pages 76–81).

We have a video that gives an overview of treatment for early prostate cancer on our website. You can watch this at [macmillan.org.uk/treatingearlyprostatecancer](http://macmillan.org.uk/treatingearlyprostatecancer)
How your treatment is planned (MDT)

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. These include:

- your general health
- the stage of the prostate cancer (see pages 18–21)
- your Gleason score (see page 21)
- your PSA level (see page 12)
- the likely side effects of treatment.
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 ask you your views about the treatment(s) before a treatment decision is made.

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

Robert

Second opinion

Your MDT uses national treatment guidelines to decide on 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.
Treatment decisions

Not having treatment straight away
You may be advised not to have treatment straight away but to be monitored instead with active surveillance or watchful waiting (see pages 35–39).

Although blood tests and biopsies can find prostate cancer at a very early stage, it isn’t possible to tell whether the cancer is going to grow and cause symptoms. The risk group of your cancer (see page 22) can give your doctors more information, but they will not be able to predict the exact outcome.

Many prostate cancers grow very slowly and a small, early-stage prostate cancer may never cause any problems in a man’s lifetime.

The treatments for prostate cancer can cause side effects such as erection problems or incontinence. For some men, these may be worse than the effects of the cancer. Your doctors may advise waiting to see whether the cancer is likely to cause problems rather than giving treatment straight away.

Choosing between two or more treatments
If you have early prostate cancer, 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.

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.
Choosing between radiotherapy and surgery

You may be asked to choose between having surgery or radiotherapy. Although your treatment is aimed at curing the cancer, you may want to think about the treatment you could have if the cancer came back.

If you have radiotherapy, it isn’t usually possible to have surgery at a later date. This is because scar tissue from the radiotherapy makes surgery difficult. However, if you have surgery, you can have radiotherapy afterwards. It’s important to talk this through with your doctor or nurse before making your decision.

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

We’ve highlighted the advantages and disadvantages of individual treatments for early prostate cancer in green boxes at the end of each treatment section.
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 straight away, 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.
Active surveillance

Active surveillance means that your doctors monitor you regularly. You will have:

• an MRI scan when you start active surveillance if you have not had one before

• a digital rectal examination every 6–12 months

• blood tests every 3–6 months to check your PSA levels.

• a prostate biopsy at 12 months or an MRI scan.

They will also ask if you have any new symptoms.

If any of the tests show that the cancer is starting to grow, your doctors will recommend surgery or radiotherapy to cure the cancer. If the cancer isn’t growing, it’s safe to continue with active surveillance.

You can read more about the tests used during active surveillance in our booklet Having tests for prostate cancer.
Understanding early (localised) prostate cancer
Advantages of active surveillance

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

• If the cancer progresses during active surveillance, treatment is usually given with the aim of curing the cancer.

Disadvantages of active surveillance

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

• You may need treatment anyway if your cancer grows.

• Some cancers that progress during active surveillance may not be curable but can be controlled with long-term hormonal therapy.
Watchful waiting

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.

Unlike active surveillance (see pages 35–37), you won’t need a scan or prostate biopsy unless your cancer starts to grow.

If you develop symptoms or your PSA level rises, your GP will refer you back to the specialist at the hospital, who will usually recommend hormonal therapy (see pages 71–75). This can help to control the cancer. If there’s no sign that the cancer is progressing, it’s safe to continue with watchful waiting.

Our booklet *Having tests for prostate cancer* has more information about these tests.
Advantages of watchful waiting

- It avoids the complications and side effects of surgery or radiotherapy.

Disadvantages of watchful waiting

- You may find it difficult to accept that your cancer is not being treated.
- Some men will need treatment anyway if their cancer progresses.
- If treatment is recommended after a period of watchful waiting it is usually given with the aim of controlling the cancer rather than curing it. However, the cancer can often be controlled for several years before additional treatment is needed.
Surgery

Surgery to remove the prostate gland is called a radical prostatectomy. 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 and the possible side effects. Your doctor should also tell you about other treatments, such as radiotherapy, that may be suitable for you and as effective.

Open radical prostatectomy

The surgery is carried out by a urologist. In an open radical prostatectomy the urologist will remove the whole prostate gland usually through a cut made in the tummy (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.

The aim of the surgery is to get rid of all of the cancer cells. It’s only done when the cancer is thought not to have spread beyond the prostate.

After this operation you may be unable to have and maintain an erection; this is called 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). You can read more about these side effects on pages 91–97.
Sometimes it’s possible to do a type of operation called a nerve-sparing prostatectomy, which reduces the risk of some of these problems. 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 by making 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 your tummy, which is then filled with carbon dioxide gas. The surgeon 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. The surgeon uses specially designed instruments to cut away the prostate gland from surrounding tissues. The prostate gland is then removed through one of the 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 and the instruments, they are attached to robotic arms. The surgeon controls the robotic arms, which can move very delicately, steadily and precisely.

This type of surgery 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.
'I was quite shocked when I was diagnosed. I just wanted to get rid of it so I had the operation – a radical prostactectomy procedure. The consultant explained it was quite an intricate operation and it could affect me in lots of different ways thereafter, but even so, I had the operation. I was lying on a table and the doctors were on a computer operating a machine next to me.'

Richard

**After your operation**

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’ve had a laparoscopic prostatectomy 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 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 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.

Lots of studies have looked at how many men might have problems getting an erection following a nerve-sparing radical prostatectomy. The numbers tend to vary as it depends on different factors, such as:

- whether you had erection problems before treatment
- your age
- 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 further treatment after surgery, such as hormonal therapy (see pages 71–75) or radiotherapy (see pages 49–70). There are various ways of coping with erection problems and these are discussed on pages 91–96.
Treating prostate cancer
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 97).

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 called 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 on bending, coughing, sneezing or during 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 open prostatectomy

• It may cure the cancer.
• It may mean that you avoid the need for further treatments such as radiotherapy and hormonal therapy.
• It may prolong the life of men with fast-growing cancers.
• If you had urinary symptoms before surgery, these may improve after surgery.
• Doctors can assess the success of the surgery by measuring your PSA level. This should drop to less than 0.1ng/ml a few weeks after surgery.

Disadvantages of open prostatectomy

• There may be a small risk of problems after the surgery, such as bleeding or infection.
• Surgery may cause long-term problems with erectile dysfunction and incontinence.
Advantages of laparoscopic prostatectomy

• Laparoscopic 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.

• Laparoscopic and robotic surgery are more complicated to carry out than open surgery. This may mean that they don’t have as good long-term outcomes.
Radiotherapy

Radiotherapy treatment to the prostate gland is known as radical radiotherapy. The aim is to destroy the cancer cells, while doing as little harm as possible to nearby tissues, such as the bladder or the back passage (rectum).

Radiotherapy for prostate cancer can be given in different ways.

**External beam radiotherapy** – This is when radiotherapy is given externally from a machine (see pages 51–59). It’s the most common way of giving radiotherapy for prostate cancer.

**Brachytherapy** – This is when radiotherapy is given internally into the tumour (see pages 61–70). There are two types of brachytherapy:

- Permanent seed brachytherapy (sometimes known as low-dose rate LDR brachytherapy).
- High-dose rate (HDR) brachytherapy.

Brachytherapy may be given together with external beam radiotherapy.

External beam radiotherapy and brachytherapy appear to be equally effective in curing prostate cancer.
You will sometimes be given hormonal therapy as well as radiotherapy (see pages 71–75). If you have intermediate-risk prostate cancer (see page 22) this can make the treatment more effective. It may be given before, during and/or after your radiotherapy. Your doctors will let you know if you need hormonal therapy and how long you need to take it for.

**External beam radiotherapy**

External beam radiotherapy is given in the hospital radiotherapy department (see photo opposite). It’s usually given as daily sessions from Monday–Friday, with a rest at the weekend. The course of treatment may last from 4–8 weeks.

**Planning external radiotherapy**

External beam radiotherapy is planned by an oncologist. 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 through 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. 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. 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 techniques 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 will have to lie still for a few minutes during the treatment.

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

Ray
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. You might hear some of the following terms used by your healthcare team when they discuss your treatment with you.

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 to a greater extent than conformal radiotherapy. It allows different doses of radiotherapy to be given to different parts of the treatment area. Tomotherapy® combines IMRT with a CT scan so each treatment is very accurate.

Image guided radiotherapy (IGRT) makes sure that each treatment is targeted as accurately as possible. Images are taken just before or during a radiotherapy treatment. They are used to make adjustments to the treatment area, making it very precise.

Stereotactic ablative radiotherapy (SABR) allows large doses of radiotherapy to be given to small areas very precisely. It is used for some men with prostate cancer. There are different machines that can be used to give SABR. The linear accelerator (linac) that delivers standard radiotherapy can be used to give SABR. There are also specially designed linacs for SABR, which are known by their brand name, such as CyberKnife®. Because SABR treats smaller areas and is very accurate, fewer treatments (usually between 4–7) are needed. SABR is being evaluated in a trial to compare it to standard radiotherapy.
Proton beam therapy uses a different type of radiation. It gives a very precise dose of radiotherapy to the prostate. It is not currently available in the UK. Trials haven’t shown any advantage over standard radiotherapy.

**Side effects of external beam radiotherapy**
Most of the side effects of external beam 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 balance this with regular, gentle exercise, which will give you more energy.

“For the first time in my life I was tired out of doing nothing. I was used to running six miles and feeling ready for another run – now I was worn out by lunchtime. Despite this, I walked my dog at least once a day for 15–20 minutes. The combination of mild exercise, fresh air and seeing the world around me started what became a fast recovery.’

Paul
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 your 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 beam 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 of external radiotherapy
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.

Erection problems
Radiotherapy for prostate cancer can cause the inability to have an erection (erectile dysfunction). 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 a period of 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 91–96).

We have a booklet called *Managing the late effects of pelvic radiotherapy in men*, which tells you more about these effects and what can help.

Infertility
Radiotherapy to the prostate can also cause permanent infertility. Some men find this very difficult to cope with. If you still want to father children naturally, you may be able to store sperm before treatment starts (see page 97).
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 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 96.

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 122 for details).
Advantages of external beam radiotherapy

• It may cure the prostate cancer.

• It may prolong the life of men who have fast growing cancers.

• It is less invasive than having a prostatectomy.

Disadvantages of external beam radiotherapy

• It can cause erection problems and infertility.

• 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 develop incontinence.

• It may take some time before doctors know whether the treatment has been successful. They will check your PSA level to find out how successful the treatment has been. This should drop but it can take some time, depending on whether you have had radiotherapy on its own or with hormonal therapy. Ask your specialist for more information about this.

• After radiotherapy you probably won’t be able to have surgery. This is because the scar tissue from radiotherapy makes surgery too difficult.

• As the prostate gland is left in place, there is a possibility that prostate cancer may occur again in the prostate gland in the future.
Brachytherapy

This type of radiotherapy is also called internal radiotherapy, implant therapy or seed implantation.

There are two ways of giving brachytherapy:

- **Permanent seed brachytherapy.** This is sometimes known as low-dose rate (LDR) brachytherapy. This uses small, radioactive metal ‘seeds’ that are inserted into the tumour so that radiation is released slowly. The seeds are not removed but the radiation gradually fades away over about six months. There is no risk of it affecting other people.

- **High-dose-rate (HDR) brachytherapy.** This involves placing thin plastic or metal 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.

Men who have early prostate cancer may have brachytherapy on its own or with external beam radiotherapy and/or hormonal therapy. Brachytherapy only carried out in specialist hospitals in the UK.

Brachytherapy may not be suitable for men with very large prostates. However, some men can be given hormonal therapy to reduce the size of their prostate before brachytherapy is given.
Permanent seed brachytherapy
Permanent seed brachytherapy is the most common type of brachytherapy.

Planning permanent seed brachytherapy
Before the seeds are put into the prostate gland, the doctors will do a scan of your prostate gland to confirm its exact size and position.

You may be asked to follow a special diet for 24 hours before the scan and you may be given an enema. This is to make sure your bowel is empty so that the ultrasound picture is as clear as possible.

The scan is usually carried out in the operating theatre and may be done under a local (spinal or epidural) anaesthetic or sometimes a general anaesthetic. Your doctor passes an ultrasound probe into your rectum to take pictures of your prostate. The doctor uses the pictures to decide how many radioactive seeds are needed and exactly where they should be placed.

Implanting the radioactive seeds
The procedure to put the radioactive seeds into your prostate gland may be carried out on the same day as your planning or a few weeks later.

The seeds are put in while you are under a general anaesthetic. An ultrasound probe is inserted into the rectum to show the prostate. The doctor then uses special needles to insert the radioactive seeds, through the skin between your testicles and back passage (anus), into your prostate gland. The needles are used to guide the seeds to your prostate gland. Once the seeds are in place, the doctor removes the needles and the ultrasound probe. The whole procedure usually takes about an hour.
'I was diagnosed with prostate cancer 10 years ago now and was one of the first people to be treated with brachytherapy at my hospital. It’s like having radioactive seeds planted in your prostate where the tumour is. The side effects of treatment tailed off after about three months.'

Harry

You’ll be given antibiotics after the procedure to prevent infection. Most men go home on the same day, as soon as they’ve recovered from the anaesthetic and are able to pass urine normally. You will not be able to drive yourself home because of the anaesthetic so make sure someone else can do this. Occasionally, you may have to stay overnight.

You should avoid heavy lifting or strenuous physical activity for 2–3 days after the procedure.

All of the radioactivity from the seeds is absorbed within the prostate, so it’s completely safe for you to be around other people. But as a precaution, you should avoid long periods of close contact with women who are or could be pregnant, and children, particularly for the first few months.
It’s safe for children to be in the same room as you. You can hold or cuddle them for a few minutes each day, but don’t let them sit on your lap for long periods, for example while watching a film. Your specialist will tell you about the precautions you should take.

Although the seeds stay permanently in the prostate gland, there is a tiny chance of a single seed being passed in the semen during sex. So it’s advisable to use a condom for the first few weeks after the seeds have been put in. During this time, the semen may be coloured black or brown. This is normal and is due to bleeding that may have occurred during the procedure. Double-wrap used condoms and dispose of them in a dustbin.

**High-dose-rate (HDR) brachytherapy**

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 overnight to have this treatment.

The specialist inserts thin metal or plastic tubes, through the skin between your testicles and back passage, into your prostate gland.

Before the tubes are put in, your doctors 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 for your treatment and exactly where they should be placed.
Once the scan is done, your specialist will put the tubes that are used to give you the brachytherapy into your prostate gland. A CT or MRI scan is taken so your specialist can work out how much radiation to give you.

After the dose has been worked out, a machine is used to insert the radioactive material into the tubes. A computer monitors how long the radioactive material stays in place for, which is usually minutes. This may be done while you are asleep with a general anaesthetic or 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. 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 some 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.
Understanding early (localised) prostate cancer
At the end of each treatment session, the radioactive material is returned to the machine. Once all the treatment has been completed the tubes are removed.

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

HDR brachytherapy is usually given with a course of external radiotherapy but it may be given on its own.

**Side effects of brachytherapy**

Brachytherapy causes similar side effects to external radiotherapy (see pages 55–58).

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 as with external radiotherapy (see page 57). But your risk may be higher if you’re having external beam radiotherapy or hormonal therapy as well as brachytherapy. 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 91–96.
Fertility
Brachytherapy may cause infertility in some men (see page 97).

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

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
Blood in your urine
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.

Unable to pass urine
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
This may affect a small number of men. There’s more information about managing incontinence on page 96.
Other problems
Some men find they have pain or discomfort when they pass urine, that they need to pass urine more often, or they have a weaker urine stream. This usually happens with permanent seed therapy and is due to the radiation from the seeds in the prostate. It improves over 3–12 months as the seeds lose some of their radioactivity. Drink plenty of fluids and avoid caffeine to help reduce these effects.

Most men will be able to return to their normal activities 1–2 weeks after treatment. But your recovery will take longer if you have external beam radiotherapy as well, for example after high dose rate brachytherapy.
Advantages of brachytherapy

• It may cure prostate cancer.

• Permanent seed brachytherapy usually only involves one session to plan and implant the seeds rather than a course of treatment, which is needed with external beam radiotherapy.

• Side effects, such as diarrhoea, are less common with brachytherapy compared to external beam radiotherapy.

Disadvantages of brachytherapy

• Bladder-related side effects may be more severe with brachytherapy compared to external beam radiotherapy. These symptoms usually improve over 3–12 months.

• A general anaesthetic is needed for the procedure and this has risks.

• After brachytherapy you probably won’t be able to have surgery. This is because the scar tissue from radiotherapy makes surgery too difficult.

• As the prostate gland is left in place, there is a possibility that another prostate cancer could develop years later.
Hormonal therapy

Hormonal therapy may be given to treat men with early (localised) prostate cancer

• if they aren’t well or fit enough for surgery or radiotherapy

• if their cancer starts to progress while they are being monitored using watchful waiting (see pages 38–39)

• if they are having radiotherapy.

It may be given before radiotherapy to help shrink the tumour. This is known as neo-adjuvant treatment. It may also be given during or after radiotherapy to reduce the chance of the cancer coming back. This is known as adjuvant treatment.

If you are having hormonal therapy, your specialist will tell you when you will have it and how long for.

Hormonal therapies can be given as injections or tablets.

Injections

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

• goserelin (Zoladex®)

• leuprorelin (Prostap®)

• triptorelin (Decapeptyl®).
Goserelin is given as a small pellet that is injected under the skin of the tummy (abdomen). Leuprorelin and triptorelin are given as liquids that are injected under the skin or into a muscle. The 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:

- flutamide (Chimax®, Drogenil®) – this is taken three times a day
- bicalutamide (Casodex®) – this is taken once daily.

Anti-androgen tablets can be given alone or they may be 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.
Side effects of hormonal therapy

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 arrange 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. 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.

Other effects
Hormonal treatment can 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 97.

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.
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) and a lowered sex drive, hot flushes and breast swelling.
Research – clinical trials

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

• test new treatments, such as new chemotherapy drugs, 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.

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

‘The oncologist explained that there was a trial going on and that I fitted the criteria. It involved having radiotherapy with hormonal treatment with different amount of doses over different time scales. After it had been comprehensively explained to us, we were given paperwork to read. We then went back for another chat with a research nurse and finally agreed to go ahead with it.’

Andrew
Blood and tumour samples

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

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

Prostate cancer treatments and clinical 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.

Cryotherapy

Cryotherapy is available as a treatment for early prostate cancer as part of a clinical trial. It is only carried out in some hospitals in the UK.

It’s suitable for very small prostate cancers and can’t be used for cancers near the outer edge of the prostate.
Cryotherapy is carried out under general or spinal anaesthetic. A number of metal probes are put through the skin and into the affected area of the prostate gland. The probes contain liquid nitrogen, which freezes and destroys the cancer cells. Local anaesthetic is used to numb the treatment area, but the treatment can still cause pain.

After the procedure, a tube (catheter) is inserted into the bladder through the skin of the abdomen to drain urine. This is left in place for 1–2 weeks. You may need painkillers for a few days. Men who’ve had this treatment can have radiotherapy or surgery if their cancer comes back.

The possible side effects of cryotherapy include erection problems and urine leakage (incontinence). Long-term side effects are not yet known.

**High-intensity focused ultrasound (HIFU) treatment**

This is sometimes used as a treatment for early prostate cancer. It’s given as part of a clinical trial so that doctors can find out more about its side effects and how helpful the treatment is.

HIFU treatment is given under a general or spinal anaesthetic. A probe is inserted into the back passage (rectum). The probe produces a high-energy beam of ultrasound. This heats the affected area of the prostate gland, destroying the cancer.

The probe is surrounded by a cooling balloon to protect the normal prostate tissue from damage.
After HIFU treatment you’ll have regular PSA blood tests (see page 12). If your PSA remains raised you’ll be offered a different type of treatment, such as radiotherapy or surgery.

The short-term side effects of HIFU treatment can include urine infections, leakage of urine, erection difficulties and rarely, damage to the bowel wall. This may need to be repaired with surgery. The long-term side effects of HIFU treatment are not yet known.

Your doctor will tell you more about these treatments and any trials if they are suitable for you.
AFTER TREATMENT FOR PROSTATE CANCER

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After treatment – follow-up

If you have surgery or radiotherapy you’ll have regular check-ups after your treatment finishes. These will probably continue for several years and will usually involve regular PSA tests (see page 12). If you are having ongoing hormonal therapy, you will continue to be monitored at regular intervals.

You may be seen regularly by your cancer specialist or you may have a PSA test at your GP surgery. It can be useful to 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 121–126 during this time.

Occasionally cancer may come back after surgery or radiotherapy. If this happens, further treatment can be given. Your doctor will discuss this with you.
Beginning to recover

Many men survive early prostate cancer. But the 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 91–97).

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 make just a few changes or you may want to 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 try to give up.

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. Walking, hiking, cycling or swimming are all good options. Activities like gardening, dancing and playing sport are also very effective.

You may find our booklets Giving up smoking and Physical activity and cancer treatment helpful.
‘I had changed my lifestyle right at the very start. So as well as learning to eat the right foods and knowing the things to avoid, I set myself a regular routine of exercising several times in the week.’

Andy

Reducing 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 hobby or an evening class. You may find it helpful to write a journal or online blog.

Being 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.
Getting help and support

Different people can help you during and after your treatment.

**Practical help**
If you need 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 urinary catheter, the district nurses can visit you at home.

**Emotional help**
There’s also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families.

Our cancer support specialists on 0808 808 00 00 can tell you more about counselling and can let you know about services in your area.

**Support groups**
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 across the UK.
Online support
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 your experience, ask questions, and get or give advice based on your prostate cancer experience. But do remember that if you need medical advice, you should speak to your specialist team.

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 the side effects of treatment

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

Sexual problems and 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 with a partner also find it difficult to talk to them because of 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. Over the next pages we will list practical ways to help overcome ED, and your doctor can give you information about these. Most hospitals also have specialist nurses who can discuss these issues with you.

‘They try not to do too much damage but the nerves that run between the spine and the penis were cut during the operation and I am no longer able to have an erection. I chose to take that risk after discussing it with my wife. I use either injection or machine to get an erection. Even my consultant said you need a sense of humour.’

Neil

**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. They all have similar benefits and risks.
Sildenafil (Viagra®) tablets produce an erection by increasing the blood supply to the penis. Viagra is usually taken 30–60 minutes before sex, on an empty stomach. Then, 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 either once a day or just when needed. Your doctor will discuss the differences between these medicines with you. You take the ‘as-needed’ preparation 30 minutes to 2 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 all 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 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, the 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 the risks and treatments for priapism.
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 30 minutes at a time, but it can be used as many times as you want, as long as you allow 30 minutes 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 121–122.
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 contact one of the organisations on pages 121–126.

Our booklet *Sexuality and cancer – information for men* discusses all of the above 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 122) 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 (see page 122).
Infertility

Most treatments for prostate cancer are likely to cause infertility, which means you will no longer be able to father a child. 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 booklet Cancer treatment and fertility – information for men.

Breast swelling

Some hormonal therapies may cause breast swelling. Ask your doctor if 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 72), another option is to take a hormonal drug called tamoxifen to prevent breast swelling.
YOUR FEELINGS AND RELATIONSHIPS

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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 relationships

Your cancer experience may have improved your relationships with people close to you. Support from family and friends may have helped your 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.
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 relative or friend 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 a lot 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 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 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 SUPPORT AND WORK

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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 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 127) or Citizens Advice (see page 126). 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 126–128.

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
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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
Other useful organisations

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

Prostate information

Prostate Cancer UK
4th floor, The 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. Has three priorities: supporting men and providing information, finding answers by funding research, and leading change to raise awareness and improve care.

Prostate Cancer Support Scotland
6 Hill Street, Edinburgh EH2 3JZ
Tel 0131 603 8660
Email info@prostatescotland.org.uk
www.prostatescotland.org.uk
Provides information, advice and help on prostate health and diseases of the prostate. You can watch videos on the website and download free leaflets and booklets.

Tackle Prostate Cancer
16 Kirby Street, London EC1N 8TS
Helpline 0845 601 0766
Email helpline@tackleprostate.org
www.tackleprostate.org
Campaign run by the Prostate Cancer Support Federation, which raises awareness of prostate cancer, encourages early detection of prostate cancer, seeks to ensure that men with prostate cancer always get the best treatment whatever the stage of their disease, and strives to remove injustices in treatment pathways offered to prostate cancer patients.
The Sexual Advice Association
Suite 301, Emblem House, London Bridge Hospital, 27 Tooley Street, London SE1 2PR
Tel 020 7486 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.

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

Orchid Cancer Appeal
St Bartholomew’s Hospital, London EC1A 7BE
Tel 0203 465 5766
(Mon–Fri, 9:00–5:30)
Email info@orchid-cancer.org.uk
www.orchid-cancer.org.uk
Funds research into men’s cancers, their diagnosis, prevention and treatment. Offers free information leaflets and fact sheets, and runs an enquiry service supported by Orchid male cancer information nurses.

General cancer support organisations

Cancer Research UK
Cancer Research UK Angel Building, 407 St John Street, London EC1V 4AD
Tel 0300 123 1022
www.cancerhelp.org.uk
Has patient information on all types of cancer and has a clinical trials database.
**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 Support Scotland**  
Cancer Support Scotland,  
The Calman Centre  
75 Shelley Road,  
Glasgow G12 0ZE  
**Tel** 0800 652 4531  
**Email** info@cancersupportscotland.org  
**www.cancersupportscotland.org**  
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

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

**Maggie’s Centres**  
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.pennybrohn
cancercare.org
Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

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 mobile cancer support units, a free helpline, an ‘Ask the nurse’ service on the website and benefits advice.

Riprap
www.riprap.org.uk
Developed especially for teenagers who have a parent with cancer.

General health information

Health and Social Care in Northern Ireland
www.hscni.net
Provides information about health and social care services in Northern Ireland.

Healhttalk
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. Also 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

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.
UK Council for Psychotherapy (UKCP)
2nd Floor, Edward House,
2 Wakley Street,
London EC1V 7LT
Tel 020 7014 9955
Email info@ukcp.org.uk
wwwpsychotherapy.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

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 the following websites:

England and Wales
wwwcitizensadvice.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

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.

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.
Further information

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.

The 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.

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
The 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.

Money Advice Scotland
Tel 0141 572 0237
www.moneyadvice
scotland.org.uk

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.
Equipment and advice on living with a disability

British Red Cross
UK Office,
44 Moorfields,
London EC2Y 9AL
Tel 0844 871 11 11
Email information@redcross.org.uk
www.redcross.org.uk
Offers a range of health and social care services such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK
Ground Floor,
CAN Mezzanine,
49–51 East Road,
London N1 6AH
Tel 020 7250 8181
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org.uk
Provides information on social security benefits and disability rights. Has a number of helplines for specific support, including information on returning to work, direct payments, human rights issues, and advice for disabled students.

Disabled Living Foundation (DLF)
Disabled Living Foundation,
Ground Floor, Landmark House,
Hammersmith Bridge Road,
London W6 9EJ
Tel 0300 999 0004
(Mon–Fri, 10am–4pm)
Email helpline@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Scope
6 Market Road,
London N7 9PW
Tel 0808 800 3333
(Mon–Fri, 9am–5pm)
Email response@scope.org.uk
www.scope.org.uk
Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.
Support for carers

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

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.

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 and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it.

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 Jim Barber, Consultant Clinical Oncologist and our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Mark Beresford, Consultant Clinical Oncologist; Mr Alan Doherty, Consultant in Urology; Anne Jackson, Macmillan Urology Clinical Nurse Specialist; Mrs Sarah James, Professional Officer, the Society and College of Radiographers; Dr James Wylie, Consultant Clinical Oncologist; and the people affected by cancer who reviewed this edition.

Sources


Can you do something to help?

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

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

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

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

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

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

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

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

Call us to find out more

0300 1000 200
macmillan.org.uk/getinvolved
Please fill in your personal details

Mr/Mrs/Miss/Other
Name
Surname
Address

Postcode
Phone
Email

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

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

Valid from Expiry date

Issue no Security number

Signature

Date / /

Don’t let the taxman keep your money

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

☐ I am a UK 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
More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

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 there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk
