UNDERSTANDING KIDNEY CANCER
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**Understanding kidney cancer**

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About this booklet

This booklet gives information and support to people who have kidney cancer, and their families. We hope it answers some of your questions about the diagnosis and treatment of kidney cancer, and helps you deal with some of the feelings you may have.

At the end of this booklet are some useful addresses and websites (pages 68–75), and a page to fill in with your questions for your doctor or nurse (page 76).

We can’t advise you about the best treatment for you. This information can only come from your own 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

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?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. Cancer isn’t a single disease with a single cause and a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Although cells in different parts of the body may look different and work in different ways, most repair and reproduce themselves in the same way. Normally, cells divide in an orderly and controlled way. But if for some reason the process gets out of control, the cells carry on dividing, and develop into a lump called a **tumour**. Tumours can be either **benign** (non-cancerous) or **malignant** (cancerous). Doctors can tell whether a tumour is benign or malignant by removing a piece of tissue (biopsy) and examining a small sample of cells under a microscope.
In a **benign tumour**, the cells do not spread to other parts of the body and so are not cancerous. However, they may carry on growing at the original site, and may cause a problem by pressing on surrounding organs.

In a **malignant tumour**, the cancer cells have the ability to spread beyond the original area of the body. If the tumour is left untreated, it may spread into surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system.

When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a **secondary cancer** or a **metastasis**.

**The lymphatic system**

The lymphatic system is part of the immune system – the body’s natural defence against infection and disease. It’s made up of organs such as bone marrow, the thymus, the spleen, and lymph nodes. The lymph nodes throughout the body are connected by a network of tiny lymphatic tubes (ducts). The lymphatic system has two main roles: it helps to protect the body from infection and it drains fluid from the tissues.

Sometimes kidney cancer can spread to the lymph nodes surrounding the kidney.
About kidney cancer

Each year, over 9,000 people in the UK are diagnosed with kidney cancer. It affects more men than women. Kidney cancer is more common in people over 60 and rarely affects people under 40. Usually only one kidney is affected, and it’s rare for cancer to affect the other kidney.

Wilms’ tumour (or nephroblastoma) is an uncommon type of kidney cancer that can affect very young children.

We have a fact sheet about Wilms’ tumour, and a booklet, A parent’s guide to children’s cancers, which have more information.

Cancer of the kidney isn’t infectious and can’t be passed on to other people.
The kidneys

Most people have two kidneys. They sit at the back of the body, one on each side, just underneath the ribcage. The kidneys filter the blood and remove waste products, which they convert into urine.

Urine drains from each kidney, through a tube called a ureter, to the bladder where it is stored. When you’re ready to pass urine it leaves the body through another tube called the urethra.
Blood is carried to the kidney through a blood vessel called the renal artery. Renal means ‘to do with the kidney’. After the blood has been filtered by thousands of tiny filters called nephrons, it travels back to the rest of the body through the renal vein.

The kidneys also help to control the balance of fluid, salt and minerals in the body and to maintain blood pressure.

The kidneys are contained in a fibrous covering called the Gerota’s fascia and surrounded by a layer of fat. The outer part of the kidney that makes urine is called the cortex. The inner part that collects urine is called the medulla.

On top of each kidney sits a small gland called the adrenal gland, which produces important hormones.
Types of kidney cancer

There are different types of kidney cancer. About 90% of kidney cancers (9 out of 10) are renal cell cancers (RCC), sometimes called renal adenocarcinoma. They start in the cells that line very small tubes, called tubules, in the kidney cortex (see diagram on page 8).

This booklet is about renal cell cancer, which we call kidney cancer.

There are different types of renal cell cancer. The most common type is clear cell renal cancer. Less common types are papillary, chromophobe and collecting duct renal cancer.

Another type of cancer that can affect the kidneys starts in the cells that line the renal pelvis, where the kidney joins with the ureter. These cancers, sometimes called transitional cell cancers, behave and are treated differently to renal cell cancer.

We have a fact sheet about cancer of the ureter and renal pelvis.

You can contact our cancer support specialists on 0808 808 00 00 or look on our website for more information about rarer types of kidney cancer.
Risk factors and causes

The causes of kidney cancer are unknown, but research is going on to try to find out more. There are certain things that can affect the chances of developing kidney cancer. These are called risk factors. Having a risk factor doesn’t necessarily mean you’ll get kidney cancer.

**Age**

The risk of kidney cancer increases with age and most cases happen in people over 60.

**Smoking**

The longer a person smokes and the more tobacco they smoke, the greater their risk of developing kidney cancer. Risk goes down when a person stops smoking.

**Being overweight**

Studies show that people who are overweight have an increased risk of developing kidney cancer.

**Medical conditions**

Some medical conditions, such as high blood pressure (hypertension), may increase the risk of kidney cancer. People with advanced kidney disease, especially those who need treatment to replace what a kidney does (dialysis), have a higher risk of developing kidney cancer.
Family history

Most kidney cancers aren’t inherited. However, people who have one or more first degree relatives (parent, brother, sister or child) with kidney cancer may have a higher than average risk of getting kidney cancer.

Genetic risk

Some rare genetic conditions where people have an inherited faulty gene can increase the risk of developing kidney cancer. These include von Hippel-Lindau disease, hereditary papillary renal cell carcinoma (HPRCC) and Birt-Hogg-Dube (BHD) syndrome.

Kidney cancers that happen because of an inherited faulty gene are more likely to cause several tumours, affect both kidneys and happen at a younger age.

Exposure to certain materials at work

Exposure to certain materials at work, such as cadmium, lead or asbestos, may affect a person’s risk. An increased risk of kidney cancer has been linked to working with blast furnaces or coke ovens in the steel and coal industries. It has also been linked to working with Trichloroethylene (Tric), a petroleum by-product used in the heavy engineering industry.
Symptoms

Kidney cancers that are small don’t usually cause symptoms, because they can’t be felt or seen. Early kidney cancers are often diagnosed by chance when people are having tests or scans for some other reason.

Some possible symptoms are:

• blood in the urine (haematuria) – it’s very important to get this checked by your doctor

• a lump in an area of the kidney that’s found during an examination

• a dull pain in the side between your upper abdomen and back

• having an ongoing high temperature, night sweats, feeling very tired, or losing weight for no obvious reason.

Most people with these symptoms won’t have kidney cancer. They can be caused by other more common conditions, such as an infection or stones in the bladder or kidneys. But if you have any of these symptoms, it’s important to get them checked by your doctor.
How kidney cancer is diagnosed

Usually you begin by seeing your family doctor (GP). They will ask for a sample of your urine and may also take a blood sample for testing. Depending on the results of these tests, you’ll be referred to hospital to see a doctor who specialises in diagnosing and treating kidney and bladder problems (a urologist).

If you have blood in your urine (haematuria) you may be referred to a ‘one-stop’ haematuria clinic. At this clinic, all the tests needed to make a diagnosis can often be carried out at the same time and you can go home on the same day.

At the hospital

You’ll see a urologist or a specialist nurse who will ask you about your symptoms and general health. They’ll also examine you and arrange some of the following tests:

Ultrasound scan
This test can be very helpful in diagnosing cancer of the kidney. It uses sound waves to build up a picture of the inside of the tummy (abdomen), including the kidneys. It’s a painless test and only takes a few minutes. Once you’re lying comfortably on your back, a gel is spread onto your abdomen. A small device, which produces sound waves, is rubbed over the area. The sound waves are turned into a picture by a computer.
Ultrasound can be used to look for changes in the shape of the kidneys. It can help to show if a lump is a cyst (a fluid-filled lump) or a tumour. It can also be used to show the position of a cancer and measure its size.

**IVU (intravenous urogram) or IVP**
This test shows up anything unusual in the kidneys or urinary system. It’s done in the hospital x-ray department and takes about an hour. A dye is injected into a vein in your arm, which travels through the bloodstream to the kidneys. The doctor can watch on a screen how the dye passes through the kidneys and can pick up any problems. The dye will probably make you feel hot and flushed for a few minutes, but this feeling goes away after a short time.

This procedure is often combined with a CT scan (see below) and is known as a **CT urogram**.

**CT (computerised tomography) scan**
A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It’s important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You’ll probably be able to go home as soon as the scan is over.
How kidney cancer is diagnosed

Chest x-rays
These are often taken to check the health of your heart and lungs.

Cystoscopy
You may have this test to check the lining of your bladder if you have blood in your urine.

It’s usually done under local anaesthetic and takes about 20 minutes. A doctor or nurse will gently pass a thin, flexible tube with a camera and light on the end (cystoscope) through the urethra and into the bladder (see page 8). This allows them to look at the whole lining of the bladder and urethra.
You may have some soreness or mild pain when you pass urine for the first couple of days after the test. There aren’t usually any other effects.

**MRI (magnetic resonance imaging) scan**
This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet, so you may be asked to complete and sign a checklist to make sure it’s safe for you.

The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins. You should also tell your doctor if you’ve ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it’s likely that you won’t be able to have an MRI scan. In this situation, another type of scan can be used.

Before the scan, you’ll be asked to remove any metal belongings, including jewellery. Some people are given an injection of dye into a vein in the arm, which doesn’t usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly.

During the test you’ll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It’s painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It’s also noisy, but you’ll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.
Guided biopsy
This is done if you need to have a sample of tissue taken from the kidney (a biopsy). The doctor uses an ultrasound scanner or CT scanner to guide them to the exact area of kidney where the biopsy will be taken.

The doctor will inject some local anaesthetic into the skin to numb the area over the kidney. You’ll then have an ultrasound scan or a CT scan. Using the picture from the scan the doctor gently guides the needle through your skin into the kidney. A small sample of tissue is drawn into the needle before it’s removed. The sample is sent to the laboratory to be examined under a microscope.

You may need to stay in hospital for a few hours, or overnight, after this procedure.

Blood tests
Samples of your blood will be taken to check your general health, the number of cells in your blood (your blood count), and to see how well your kidneys and liver are working.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, family or a close friend. Your specialist nurse or one of the organisations listed on pages 68–70 can also provide support. You can also talk things over with one of our cancer support specialists on 0808 808 00 00.
Understanding kidney cancer

Staging and grading

Staging

The stage of a cancer describes its size and whether it has spread. Once your doctors know the stage of the cancer, they can decide on the most appropriate treatment for you.

The most commonly used staging system for kidney cancer is the TNM system:

- **T** refers to the tumour size.
- **N** refers to whether lymph nodes are affected.
- **M** refers to whether the cancer has spread to other parts of the body (metastases).

**Tumour size (T)**

- **T1** – the cancer is no larger than 7cm and is inside the kidney.
  - **T1a** – the cancer is no larger than 4cm and is inside the kidney.
  - **T1b** – the cancer is between 4–7cm and is inside the kidney.
- **T2** – the cancer is larger than 7cm and is inside the kidney.
  - **T2a** – the cancer is between 7–10cm and is inside the kidney.
  - **T2b** – the cancer is larger than 10cm and is inside the kidney.
• **T3** – the cancer has spread into the fat around the kidney but not beyond the fibrous tissue (Gerota’s fascia), or the cancer has spread into major veins close to the kidney (the vena cava and renal vein).

  • **T3a** – the cancer has spread into the renal vein or the fat around the kidneys but not the fibrous tissues (Gerota’s fascia).

  • **T3b** – the cancer has spread into part of a large blood vessel called the vena cava, which is below the diaphragm.

  • **T3c** – the cancer has spread into the part of the large blood vessel (the vena cava) that is above the diaphragm, and it’s growing into the wall of the blood vessel.

• **T4** – the cancer has spread outside the fibrous tissue (Gerota’s fascia) that surrounds the kidney.

**Lymph nodes (N)**
The N refers to whether the cancer cells have spread into the lymph nodes close to the kidney.

• **N0** – there are no cancer cells in any lymph nodes.

• **N1** – there are cancer cells in one or more lymph nodes.

If the cancer cells have spread to the lymph nodes, the nodes are said to be positive.
Metastases (M)
• **M0** – the cancer cells have not spread to other parts of the body.

• **M1** – the cancer cells have spread to other parts of the body. If kidney cancer spreads, it’s most likely to go to the bones, the lungs, the liver or the brain. If the cancer has spread, it’s called secondary or metastatic kidney cancer.

Number staging

The T, N and M stages may be grouped together to give an overall stage for the cancer. These range from stages 1–4.

**Stage 1**
The cancer is 7cm or less and is inside the kidney. There is no spread to lymph nodes or other organs.

**Stage 2**
The cancer is larger than 7cm and is inside the kidney. There is no spread to lymph nodes or distant organs.

**Stage 3**
The cancer is inside the kidney but has spread to one or more lymph nodes.

The cancer has begun to spread outside the kidney – it may have spread into one of the major veins close to the kidney (the renal vein or the vena cava). Or the cancer has spread into the fat that surrounds the kidney. It may or may not have spread to one or more lymph nodes.
**Stage 4**
The cancer has grown through the fibrous tissue outside of the kidney. It may or may not have spread to one or more lymph nodes.

The cancer has spread to other parts of the body. It can be any size and may have grown into the tissue outside the kidney.

**Grading**

Grading refers to the appearance of the cancer cells under the microscope. The grade gives an idea of how the cancer may behave.

The Fuhrman system is the most common grading system for kidney cancer. It ranges from 1–4; the higher the number, the more abnormal the cells look. A grade 1 cancer is usually slow-growing and is less likely to spread than a higher grade, such as a grade 4 cancer.
Treatment overview

**Surgery** (see pages 32–36) is the main treatment for kidney cancer that hasn’t spread outside the kidney (stages 1 and 2). If the tumour is small, the surgeon will usually only remove the part of the kidney containing the tumour. But in some cases, depending on the size of the cancer, the whole kidney may need to be removed (nephrectomy). This is sometimes done using keyhole surgery (see pages 33–34).

In some situations, treatments that destroy the cancer cells using heat (radiofrequency ablation, see pages 37–38) or extreme cold (cryotherapy, see page 38) can be used to treat small kidney cancers instead of an operation.

There is currently no standard treatment given to reduce the risk of kidney cancer coming back after surgery (called adjuvant treatment). But clinical trials (see pages 47–48) are trying to find out if targeted therapy or biological therapy treatments (see pages 41–44) can help reduce the risk of some cancers coming back.

**Advanced cancer**

Even when the cancer has spread outside the kidney, your surgeon may still advise you to have an operation to remove the kidney. This can help to slow down and control the cancer. You’ll usually have treatment with a targeted therapy drug as well.

When kidney cancer has spread outside the kidney and to other parts of the body the main treatment is targeted therapy. Occasionally radiotherapy (see page 45), chemotherapy or hormonal therapy treatment (see page 46) is used.
Your doctors will suggest the best treatment for you by taking into account the size of the tumour, whether it has spread and your general health.

**How treatment is planned**

In most hospitals, a team of specialists will meet to discuss and agree on the plan of treatment they feel is best for your situation. This **multidisciplinary team (MDT)** normally includes:

- a urologist – a surgeon who specialises in treating kidney cancers
- an oncologist – a specialist in cancer treatments such as chemotherapy, radiotherapy, targeted therapy drugs and biological therapy drugs
- a urology nurse specialist, who gives information and support
- a radiologist, who helps to analyse scans and x-rays
- a pathologist, who advises on the type and extent of the cancer.

Other staff are also available to help you if necessary, such as:

- dietitians
- physiotherapists
- occupational therapists
- psychologists and counsellors.

Your doctor or nurse specialist will discuss with you what the best treatment is for your particular situation, or they may offer you a choice of treatments. If you have to decide between treatments, make sure that you have enough information about
each treatment option, so that you can decide which is right for you. You may find it helps to ask questions about what is involved with each treatment and the possible side effects they may cause.

If you have any questions about your treatment, don’t be afraid to ask your doctor or the nurse looking after you.

It often helps to make a list of the questions you want to ask and to take a relative or close friend with you to help you remember what is discussed. You can use the form on page 76 to write down any questions you may have.

**Second opinion**

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.
Understanding kidney cancer
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 benefits 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 explanations repeated.

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. You can use the notes page on page 76 to do this.

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.

**The benefits and disadvantages of treatment**

Many people are frightened at the idea of having cancer treatments, particularly because of the side effects that can occur. However, these can usually be controlled with medicines. Treatment can be given for different reasons and the potential benefits will vary depending on your individual situation.

**Early-stage kidney cancer**
In people with early-stage kidney cancer, surgery is usually done with the aim of curing the cancer. Occasionally, drug treatments are also given in a clinical trial trying to find out if they reduce the risk of kidney cancer coming back.

**Advanced-stage kidney cancer**
If the cancer is at a more advanced stage, the treatment may only be able to control it, improving symptoms and quality of life. Sometimes treatment for advanced kidney cancer may help some people to live for longer.

However, for some people in this situation the treatment will have no effect on the cancer, and they will get the side effects without any of the benefits.
Treatment decisions

If you have early-stage cancer and have been offered treatment that aims to cure it, it may be easy to decide whether to accept the treatment.

However, if a cure is not possible and the treatment is being given to control the cancer for a period of time, it may be more difficult to decide whether to go ahead.

Making decisions about treatment in these circumstances is always difficult, and you may need to discuss in detail with your doctor whether you wish to have treatment. If you choose not to, you can still be given supportive (palliative) care, with medicines to control any symptoms.

It’s important that you ask your doctors and nurses any questions you have about your treatment. The more you understand about your treatment, the easier it will be for you and them.

You may find our booklet Making treatment decisions helpful.
Surgery

Surgery may be the only treatment that is needed. The most appropriate operation for your situation will depend on the size of the cancer, whether or not it has spread, as well as your general health. It’s important to discuss any operation fully with your surgeon and specialist nurse before you have it.

Removing part of the kidney (partial nephrectomy)

The surgeon removes only the part of the kidney containing the tumour. This is called a partial nephrectomy or kidney-sparing surgery. It’s usually only possible if the tumour is smaller than 4cm but may occasionally be done with larger tumours.

The aim is to remove the whole tumour while keeping as much normal kidney tissue as possible so the remaining kidney is still able to work.

A partial nephrectomy may also be carried out if it’s important to try to keep the affected kidney. This could be when you have only one working kidney or have kidney disease. People with an inherited type of kidney cancer, which increases the risk of cancer in the other kidney, may also be offered this operation.

Removing the whole kidney (nephrectomy)

This is when the surgeon removes the whole kidney and some surrounding tissue. This operation usually involves making a cut (incision) between the lower ribs on the side of the tumour. Your surgeon may also remove some of the lymph nodes close to the kidney to check if they contain any cancer cells.
You can live a completely normal life with just one kidney; it will do the work usually shared by both kidneys. Removing a kidney is a big operation, and you’ll need to be reasonably fit. This means that this type of surgery isn’t suitable for everyone.

A nephrectomy can be done using keyhole surgery (see below), which means a faster recovery.

**Keyhole (laparoscopic) surgery**

Keyhole or laparoscopic surgery can be used to remove a kidney (nephrectomy). It can also be used to do a partial nephrectomy.

In this type of surgery only small openings are made instead of one large cut (incision). The surgeon uses a special instrument called a **laparoscope** to see and work inside the tummy (abdomen).

The laparoscope is a thin tube with an eyepiece at one end, and a light and a magnifying lens at the other. It’s put into the abdomen through a small cut in the skin. Generally two to three small cuts and one larger cut are needed for the operation. The larger cut is usually made close to the belly button and is used to remove the kidney.

Sometimes the surgeon may use a highly specialised machine to help with keyhole surgery. Instruments attached to the machine are controlled by the surgeon. This allows them to carry out very precise surgery and is sometimes called robotic surgery.

The main advantage of keyhole surgery is that it leaves a small wound so recovery is usually quick. It may be used for people who aren’t fit enough to have an open operation. It appears to be as effective as removing the kidney using open surgery.
Keyhole surgery should be carried out by surgeons with specialist training and experience in using laparoscopic techniques. So, if it’s suitable for you and you choose to have this type of surgery, you may need to travel to another hospital to have the operation.

**Nephrectomy when the cancer has spread**

If the cancer has already spread to other places in the body (metastatic or secondary cancer), it may still be worth having the affected kidney removed. If the tumour in the kidney is causing symptoms such as pain or bleeding, or is affecting the balance of chemicals in your blood, taking it out may relieve this.

You may be given treatment with a targeted therapy or biological therapy drug (see pages 41–44) to try to shrink the cancer. After this, it may be possible to have an operation to remove the kidney.

Although this operation won’t usually cure the cancer, it may help other treatments to work better and help to prolong your life.

However, these possible advantages need to be weighed up against the effects of having a major operation. Deciding whether to go ahead with an operation in these circumstances can be very difficult. It’s important that you discuss the benefits and disadvantages with your doctors when making up your mind.

**Surgery to remove a secondary cancer**

Rarely, surgery may be used to remove a small secondary cancer in another part of the body, for example the lungs. This is very specialised surgery. It’s generally only possible if the cancer has spread to a limited area – usually just to one place in the body.
It’s also important that you’re fit enough to cope with the operation. Removing a secondary cancer may help to control the cancer for longer. Occasionally, it may be used to try to cure the cancer.

**After your operation**

You’ll be encouraged to start moving about as soon as possible. This is an important part of your recovery and helps to reduce the risk of complications. If you have to stay in bed, the nurses or physiotherapist will encourage you to do regular leg movements and deep-breathing exercises.

**Drips and drains**

When you get back to the ward, you’ll have a drip of fluid going into your vein until you’re able to eat and drink normally.

You’ll probably have drainage tubes from the wound to stop any excess fluid collecting; this helps the wound to heal. The tubes will only be needed for a short time and will be taken out before you go home.

Usually you will have a small tube (catheter) draining urine from your bladder into a collecting bag. This will save you having to get up to pass urine. The catheter is usually removed after a couple of days.

**Pain**

You’ll have some pain and discomfort after your operation, but this can be controlled well with painkilling drugs.

At first, you’ll probably need a strong painkiller such as morphine. This can be given to you by the nurses as injections or through a pump attached to a needle in your arm, which you
control yourself. This is called Patient Controlled Analgesia (PCA), and you’ll be shown how to use this.

Some people may have a different method of pain relief called an epidural. A fine tube is inserted into your back to the area just outside the membranes around your spinal cord, called the epidural space. A local anaesthetic can be continuously given into this space to numb the nerves in the operation area.

**Your wound**
You’ll have a dressing covering your wound or wounds. This may be left undisturbed for the first few days. After this, you’ll usually have the dressings changed if there’s some leakage from the wound. How long the wound takes to heal will depend on the type of operation you had.

**Going home**
How long you need to stay in hospital depends on the type of operation you had, how fit you are and how quickly you recover. It can range from 4–10 days.

Many people like to know how soon they’ll be able to get back to doing normal things, like shopping, gardening, driving, playing sport or going to work. Your surgeon or nurse will be able to advise you.

Before you leave hospital, you’ll be given an appointment to attend an outpatient clinic for a check-up about six weeks after your surgery. This is a good time to discuss any problems you may have after your operation.
Other treatments

Sometimes other treatments can be used to treat small (up to 3cm) kidney cancers instead of removing them with the standard operations.

These treatments are carried out through the skin (percutaneous) and tend to cause fewer side effects than a kidney operation. They also have quicker recovery times. They include:

• radiofrequency ablation (RFA, see below)
• cryotherapy (see page 38)
• high-intensity focused ultrasound (HIFU, see pages 38–39).

They may be suitable for people with smaller kidney tumours (stage T1a, see page 20) who aren’t fit enough to have standard surgery. Some people may choose to have these treatments instead of having surgery.

They may also be used in people who have a rare inherited form of kidney cancer with multiple tumours or cancer affecting both kidneys.

Radiofrequency ablation (RFA)

This uses heat to destroy the cancer cells and may need to be done more than once. You’ll be given a sedative drug before the treatment to make you feel drowsy and a local anaesthetic to numb the area over the kidney. Pictures produced by an ultrasound scan or CT scan help the surgeon to see the area of the kidney that needs treatment.
RFA may be done in the x-ray department or using keyhole surgery.

The doctor places one or more needle-like electrodes through the skin into the centre of the tumour. An electric current is then passed through the electrodes into the tumour. This heats the cancer cells and destroys them.

Side effects of RFA may include pain in the kidney area, bleeding and infection. In a small number of people, RFA may cause a blockage in the tube connecting the kidney to the bladder (ureter). It may also cause damage to the bowel.

**Cryotherapy**

Cryotherapy uses very cold temperatures to destroy cancer cells. It’s usually carried out under general anaesthetic. The surgeon places one or more probes into the centre of the tumour. A coolant is passed through the probes. This freezes and destroys the cancer cells and a small area (about 1cm) of healthy tissue around them.

Side effects may include pain in the kidney area, bleeding and infection. In a small number of people, the treatment may cause a blockage in the tube connecting the kidney to the bladder (ureter). It may also cause damage to the bowel.

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

This is a more recent treatment. It uses high-energy, high-frequency focused sound waves to produce high temperatures inside the tumour cells and destroy them. HIFU is used less often for kidney cancer than cryotherapy or RFA, so doctors know less about how effective it is.
It may be carried out under a local or general anaesthetic. Side effects may include pain in the kidney area, bleeding and infection. The treatment may need to be done more than once.

**Embolisation**

If surgery to remove the kidney isn’t possible because of your general health or because the tumour is too large, it may be possible to block off the blood supply to the tumour. This is called embolisation. It’s rarely used but can help control symptoms such as bleeding.

A thin, plastic tube (catheter) is put into a blood vessel in your groin. Then, using x-ray pictures as a guide, the surgeon threads the catheter upwards until the tip is in the artery that carries blood to the kidney. A substance is then injected through the catheter into the kidney. This blocks the blood supply to the kidney and so cuts off the supply of oxygen and nutrients to the tumour.

This treatment can sometimes cause pain in the back and a high temperature, so you may need to stay in hospital for a few days after you have it.
Targeted and biological therapy drugs

Targeted and biological therapy drugs are newer treatments used for kidney cancer. They may be given to try to shrink and control locally advanced kidney cancer or kidney cancer that has spread to other parts of the body. They may also be used if a cancer has come back (recurrence).

**Targeted therapies**

These drugs work by stopping the cancer from making new blood vessels (cancer cells need new blood vessels to grow). Targeted therapies also interfere with signals that tell cancer cells to grow.

**Sunitinib (Sutent®)**

This may be used as a first drug treatment for people who have stage 3 or 4 kidney cancer. It’s a type of drug called a *cancer growth inhibitor*.

It’s usually taken daily as a tablet for four weeks followed by two weeks off. This makes up a cycle of treatment. Your doctor may adjust the dose during your treatment.

Common side effects of sunitinib include:

- tiredness
- skin changes such as a rash
- thinning hair
• hand-foot syndrome, where the palms of the hands and soles of the feet become red, sore and sometimes swollen
• a sore mouth
• loose bowel motions
• raised blood pressure.

Sunitinib can also make the thyroid gland work less well, so during your treatment you’ll have blood tests to check this.

**Pazopanib (Votrient®) and sorafenib (Nexavar®)**
These are other cancer growth inhibitors that can be used as a first treatment for advanced kidney cancer. Like sunitinib they’re taken as a tablet.

**Everolimus (Afinitor®)**
This is also given as a tablet and is usually used as a second treatment after another targeted therapy for advanced kidney cancer has been tried.

**Temsirolimus (Torisel®)**
Temsirolimus is given as an injection into a vein (intravenously) and may also be used as a second drug treatment.

A new targeted therapy drug called **Axitinib** has recently been licensed. It works in a very similar way to sunitinib and pazopanib.

**Bevacizumab (Avastin®)**
This is a treatment known as a monoclonal antibody. It also works by stopping kidney cancers from developing new blood vessels. Bevacizumab is licensed to treat advanced kidney cancer when it’s given with another drug called **interferon** (see pages 43–44).
All these drugs are licensed to treat kidney cancer and can be used in the UK. Only sunitinib and pazopanib have been approved by the National Institute for Health and Clinical Excellence (NICE) as possible first drug treatments for kidney cancer. NICE gives advice on which new drugs and treatments should be available on the NHS.

The Scottish Medicines Consortium (SMC), which gives advice on the use of new drugs in the NHS in Scotland, hasn’t approved sunitinib as a first drug treatment but has approved pazopanib in certain situations.

As a result, some of the drugs may not be widely available and they’re often given as part of a clinical trial (see pages 47–48).

Your specialist may apply to the health board for individual funding for a drug, or if you live in England they may be available through the Cancer Drug Fund. Your specialist will discuss this with you if they think any of these drugs are suitable for you.

**We have more information on what you can do if a treatment isn’t available.**

**Biological therapies**

Biological therapy drugs work in a number of ways including encouraging the body’s immune system to fight cancer cells.

**Interferon**

Interferon can be used to treat advanced kidney cancer and is sometimes given along with bevacizumab (Avastin®).
Interferon is naturally produced by the body in small amounts and can also be made as a drug. It has different effects on the body’s immune system to help fight cancers.

The type used to treat cancer of the kidney is called interferon alpha-2a (Roferon-A®). It’s usually given three times a week by injection under the skin (subcutaneously). You, a relative or carer can be taught to give these injections at home. You can use either a pen-injection device or a pre-filled syringe, which makes it easier to give. If you need help your district nurse or GP practice nurse can give them to you.

In the first couple of weeks, interferon often causes flu-like symptoms such as chills, a high temperature, headaches, and aching in the back, joints and muscles. Your doctor can prescribe medicine, such as paracetamol, to reduce these symptoms. Another common side effect of interferon is feeling tired (fatigue).

**Aldesleukin**

Aldesleukin (Proleukin®), which used to be called interleukin-2 (IL-2), is an artificial version of a protein that occurs naturally in the body.

You’ll need to stay in hospital to have this treatment, which is given as a drip (intravenously) by a cancer doctor (oncologist). It may cause some serious side effects of the heart and lungs, so people having it are closely monitored.

Some common side effects of aldesleukin are flu-like symptoms, feeling sick or losing your appetite.

*We can send you individual fact sheets about all these drugs with more detailed information.*
Radiotherapy

Radiotherapy treats cancer by using high-energy x-rays, which destroy the cancer cells while doing as little harm as possible to normal cells. It’s most often used to try to shrink the cancer if it’s causing pain, or to treat cancer that has spread to the brain or the bones.

We have information about secondary bone cancer and secondary brain cancer.

The treatment is given in the hospital radiotherapy department as an outpatient. Radiotherapy is often given as sessions called fractions. When used to relieve symptoms, it’s usually given for a few minutes every day for a few days. Your doctor will discuss the treatment with you.

After being positioned, you’ll be left alone for a few minutes while treatment is given, but you can still talk to your radiographer through an intercom.

Side effects of radiotherapy

Radiotherapy can cause general side effects such as tiredness (fatigue). Other side effects depend on the part of the body being treated but are usually mild when the radiotherapy is given to relieve symptoms. The doctor who plans your radiotherapy (clinical oncologist) will be able to advise you about what to expect. Usually side effects disappear gradually once your course of treatment is over, but it’s important to let your doctor know if they continue.

Our booklet Understanding radiotherapy has more information about the treatment and its side effects.
Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. They work by disrupting the growth of cancer cells.

Chemotherapy is not as effective at treating kidney cancer as some other treatments, such as targeted therapy or biological therapy drugs. But you may be offered chemotherapy as part of a clinical trial or in combination with a targeted therapy or biological therapy treatment.

Our booklet Understanding chemotherapy has more information.

Hormonal therapy

Some people may be given the hormone progesterone to take daily as tablets. Progesterone treatment usually causes few side effects. Any side effects are usually mild and can include an increased appetite and weight gain. This treatment may reduce your sex drive (libido). Fluid retention may also occur, and you may notice that your feet and ankles become swollen. If this is a problem for you, it can be treated with drugs called diuretics.
Research – clinical trials

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

• test new treatments, such as new chemotherapy drugs or new targeted or biological therapy drugs

• look at new combinations of existing treatments, or change the way they are given, to make them more effective or to reduce side effects

• compare the effectiveness of drugs used to control symptoms

• find out how cancer treatments work

• see which treatments are the most cost-effective.

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

Taking part in a trial

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

Usually, several hospitals around the country take part in these trials. It’s important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.
If you decide not to take part in a trial, your decision will be respected and you don’t have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you’re treated by the hospital staff, and you’ll be offered the standard treatment for your situation.

Our booklet *Understanding cancer research trials (clinical trials)* describes clinical trials in more detail. We can send you a copy.

**Blood and tumour samples**

Blood or 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 are taking part in a trial you may also be asked to give other samples, which may be frozen and stored for future use, when new research techniques become available. These samples will have your name removed from them 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, so you are unlikely to hear the results. The samples will, however, be used to increase knowledge about the causes of cancer and its treatment. This research will hopefully improve the outlook for future patients.
Follow-up

After your treatment is completed, you’ll have regular check-ups at the hospital. Your doctor or specialist nurse will tell you how long you’ll need to have these for.

Your follow-up will usually depend on the type of treatment you had and the risk of the cancer coming back. Some people may have regular tests to check for any signs of the cancer coming back. If the cancer comes back in the kidney, it may be possible to have further surgery to remove the cancer.

Many people find they get very anxious in the time leading up to their appointments. This is natural and it may help to get support from family, friends or one of the organisations listed on pages 68–70 during this time.

If you have any problems, or notice any new symptoms between follow-up appointments, let your doctor know as soon as possible.
After treatment

You’ll probably be keen to get back to doing the things you did before your cancer diagnosis. But you may still be coping with the side effects of treatment and also with some difficult emotions (see page 52–55).

Recovery takes time, so try not to be hard on yourself.

Our booklet Life after cancer treatment discusses how to adjust to life after treatment.

Lifestyle – positive choices, helping yourself

After cancer treatment some people choose to make some positive lifestyle changes. It’s not to say you didn’t follow a healthy lifestyle before cancer, but you may be more focused on making the most of your health. We’ve included information here that may help you.

Stop smoking
If you’re a smoker, giving up smoking is one of the healthiest decisions you can make. Smoking is a major risk factor for smoking-related cancers and heart disease.

Our leaflet Giving up smoking has more information and tips to help you quit.

Keep to a healthy weight
If you feel you need to lose weight, ask your GP for advice and what your ideal weight is.

Our booklet Weight management after cancer treatment has some helpful tips.
Keeping to a healthy weight reduces the risk of some other cancers, heart problems and illnesses such as diabetes.

Here are some tips to help you lose weight:
• only eat as much food as you need
• eat a balanced diet with lots of fruit and vegetables
• eat less fat and sugar
• become more physically active.

**Eat healthily**
Eating healthily will also give you more energy and help you to recover. Try to eat plenty of fresh fruit and vegetables (five portions a day), cut down on salt and eat less red meat. Follow any advice you have been given by a dietitian.

*We have a booklet* Healthy eating and cancer *that we can send you.*

**Get physically active**
Being physically active helps to keep your weight healthy and can reduce stress and tiredness. It also reduces the risk of other health conditions.

*We have a booklet called* Physical activity and cancer treatment, *which has more information.*

**Stick to sensible drinking guidelines**
These recommend that men drink no more than three units of alcohol a day (or 21 a week) and women no more than two units a day (or 14 a week). It’s a good idea to have a few alcohol-free days each week.
Your feelings

Most people feel overwhelmed when they are told they have cancer, and have many different emotions. These are part of the process you may go through when dealing with your illness. Partners, family members and friends often have similar feelings and may also need support and guidance to help them cope.

Reactions differ from one person to another – there’s no right or wrong way to feel. We describe some of the common emotional effects of cancer here. However, reactions vary and people have different emotions at different times.

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

Shock and disbelief

Disbelief is often the immediate reaction when cancer is diagnosed. You may feel numb and unable to express any emotion. You may also find that you can only take in a small amount of information, and so you have to keep asking the same questions again and again. This need for repetition is a common reaction to shock. Some people find that their feelings of disbelief make it difficult for them to talk about their illness with family and friends. For others it may be the main topic of conversation as it’s the main thing on their mind.

You may find our booklet Talking about your cancer helpful.
Fear and uncertainty

Cancer is a frightening word surrounded by fears and myths. One of the greatest fears people have is whether they will die. Many cancers are curable if found at an early stage. When a cancer is not curable, current treatments often mean that it can be controlled for some time.

Many people are anxious about whether their treatment will work and have any side effects. It’s best to discuss your treatment and possible outcomes in detail with your doctor.

You may find that doctors can’t answer your questions fully, or that their answers sound vague. It’s often impossible for them to say for certain how effective treatment will be. Doctors know roughly how many people may benefit from a certain treatment, but they can’t predict the future for a particular person. Many people find this uncertainty hard to live with, but your fears may be worse than the reality. Finding out about your illness can be reassuring. Discussing what you have found out with your family and friends can also help.

You might find it helpful to talk to other people in your situation. Call our cancer support specialists on 0808 808 00 00 to find out if there’s a support group in your area. Or you can visit our online community at macmillan.org.uk/community to chat any time with people who know what you’re going through. Some people find some form of spiritual support helpful at this time, and you may like to talk to a spiritual or religious adviser.
Denial

Many people cope with their illness by not wanting to know much or talk much about it. If that’s the way you feel, just let your family and friends know that you’d prefer not to talk about your illness, at least for the time being.

Sometimes, however, it’s the other way around. You may find that your family and friends don’t want to talk about your illness. They may appear to ignore the fact that you have cancer, perhaps by playing down your worries and symptoms or deliberately changing the subject. If this upsets or hurts you, try telling them. Perhaps start by reassuring them that you know why they’re doing it, but that it will help you if you can talk to them about your illness.

Anger

People often feel very angry about their illness. Anger can also hide other feelings, such as fear or sadness. You may direct your anger at the people closest to you, or at the doctors and nurses caring for you. It’s understandable that you may be very upset by many aspects of your illness, so you don’t need to feel guilty about your angry thoughts or irritable moods.

Bear in mind that your family and friends may sometimes think that your anger is directed at them, when it’s really directed at your illness. It may help to tell them this, or perhaps show them this section of the booklet.
Blame and guilt

Sometimes people blame themselves or others for their illness, trying to find reasons to explain why it has happened to them. This may be because we often feel better if we know why something has happened. In most cases it’s impossible to know exactly what has caused a person’s cancer. So there’s no reason for you to feel that anyone is to blame.

Resentment

Understandably, you may feel resentful because you have cancer while other people are well. These feelings may crop up from time to time during the course of your illness and treatment. It usually helps to discuss these feelings, rather than keeping them to yourself.

Isolation and depression

There may be times when you want to be left alone to work through your thoughts and emotions. This can be hard for your family and friends, who want to share this difficult time with you. It may help them cope if you reassure them that, although you don’t feel like discussing your illness at the moment, you’ll talk to them about it when you’re ready.

Sometimes, depression can stop you wanting to talk. If you or your family think you may be depressed, discuss this with your GP. They can refer you to a doctor or counsellor who specialises in the emotional problems of people with cancer, or prescribe an antidepressant drug for you.

We have a video at macmillan.org.uk/depression that may be helpful.
If you are a relative or friend

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

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

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

Our booklet Lost for words: how to talk to someone with cancer has more suggestions if you have a friend or relative with cancer.

If you’re looking after a family member or friend with cancer, you may find our booklet Hello, and how are you? helpful. It’s based on carers’ experiences and has lots of practical tips and information.

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

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

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

Teenagers

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

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

Our booklet Talking to children 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
What you can do

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

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

Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities.

Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you’ve dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a more healthy diet, by getting fitter or by finding a relaxing complementary therapy. Our booklet Cancer and complementary therapies has more information about different therapies.

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

Many people are available to help you and your family.

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

The **hospital social worker** can give you information about social services and benefits you may be able to claim, such as meals on wheels, a home helper or hospital fares. The social worker may also be able to arrange childcare for you during and after treatment.

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

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

There’s also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.
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
Financial help and benefits

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

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

If you’re an employee and unable to work because of illness, you may be able to get Statutory Sick Pay. This is paid by your employer for up to 28 weeks of sickness, and if you qualify for it, your employer can’t pay you less.

Before your Statutory Sick Pay ends, or if you are not eligible, check whether you can claim Employment and Support Allowance. This benefit gives financial help to people who are unable to work due to illness or disability.

If you’re receiving intravenous (by injection into a vein) chemotherapy or are likely to receive it within six months, you will automatically be assessed as having limited capability for work.

Disability Living Allowance (DLA) is for people under 65 who have difficulty walking or looking after themselves (or both). You need to have had these difficulties for at least three months to qualify, and they should be expected to last for the next six months. As part of the Welfare Reform Act 2012, DLA will be
replaced by a **Personal Independence Payment** for people of working age from April 2013.

**Attendance Allowance (AA)** is for people aged 65 or over who have difficulty looking after themselves. You may qualify if you need help with personal care, such as getting out of bed, having a bath or dressing yourself. You don’t need to have a carer to be eligible, but you must have needed care for at least six months.

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

**Help for carers**

If you are a carer, you may be entitled to financial help as well. This may include **Carer’s Allowance**, which is the main state benefit for carers, and **Carer’s Credit**, which helps carers build up qualifying years for State Pension.

You can find out more about benefits from Citizens Advice, or by calling the Benefit Enquiry Line on **0800 882 200** (or **0800 220 674** if you live in Northern Ireland). The website [gov.uk](https://gov.uk) ([nidirect.gov.uk](https://nidirect.gov.uk) if you live in Northern Ireland) also has useful information.

**See our booklet Help with the cost of cancer for more detailed information. Our video at macmillan.org.uk/gettingfinancialhelp may also be useful.**
Insurance

People who have or have had cancer may find it harder to get certain types of insurance, including life and travel insurance. An independent financial adviser (IFA) can help you assess your financial needs and find the best deal for you. You can find an IFA by contacting one of the organisations on pages 71–72.

Our leaflet Getting travel insurance and our booklet Insurance may be helpful.
Understanding kidney cancer

How we can help you

Cancer is the toughest fight most of us will ever face. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

Get in touch

Macmillan Cancer Support
89 Albert Embankment,
London SE1 7UQ

Questions about cancer?
Call free on 0808 808 00 00
(Mon–Fri, 9am–8pm)

www.macmillan.org.uk

Hard of hearing?
Use textphone
0808 808 0121 or Text Relay.

Non-English speaker?
Interpreters are available.

Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.

Macmillan Support Line
Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. 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, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at macmillan.org.uk/informationcentres
Publications
We provide expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. We can send you free information in a variety of formats, including booklets, leaflets, fact sheets, and audio CDs. We can also provide our information in Braille and large print.

You can find all of our information, along with several videos, online at macmillan.org.uk/cancerinformation

Review our information
Help us make our resources even better for people affected by cancer. Being one of our reviewers gives you the chance to comment on a variety of information including booklets, fact sheets, leaflets, videos, illustrations and website text.

If you’d like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk

Need out-of-hours support?
You can find a lot of information on our website, macmillan.org.uk
For medical attention out of hours, please contact your GP for their out-of-hours service.

Someone to talk to
When you or someone you know has cancer, it can be difficult to talk about how you’re feeling. You can call our cancer support specialists to talk about how you feel and what’s worrying you.

We can also help you find support in your local area, so you can speak face-to-face with people who understand what you’re going through.
Professional help

Our Macmillan nurses, doctors and other health and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until they no longer need this help.

You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call us.

Support for each other

No one knows more about the impact cancer has on a person’s life than those who have been affected by it themselves. That’s why we help to bring people with cancer and carers together in their communities and online.

Support groups
You can find out about support groups in your area by calling us or by visiting macmillan.org.uk/selfhelpandsupport

Online community
You can also share your experiences, ask questions, get and give support to others in our online community at macmillan.org.uk/community
Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. Some people may have to stop working.

If you’ve been affected in this way, we can help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to.

We can also give you information about your rights at work as an employee, and help you find further support.

Macmillan Grants
Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much needed break.

Find out more about the financial and work-related support we can offer at macmillan.org.uk/financialsupport

Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on our Learn Zone – macmillan.org.uk/learnzone – which offers a variety of e-learning courses and workshops. There’s also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.
Other useful organisations

James Whale Fund for Kidney Cancer
46–48 King Street, Cambridge CB1 1LN
Tel 0844 474 5050 (Mon–Fri, 10am–4pm)
Email contact@jameswhalefund.org
www.jameswhalefund.org
Seeks to help reduce the harm caused by kidney cancer by increasing knowledge and awareness, providing patient information and by supporting research into the causes, prevention and treatment of the disease.

Kidney Cancer UK
Secure Hold Business Centre, Studley Road, Worcestershire B98 7LG
Tel 0844 870 7054 (Mon–Tues, 9am–3pm, Wed, 9am–12pm)
Email admin@kcuk.org
www.kcuk.org
Provides information and support for kidney cancer patients and their carers. Holds regular meetings, publishes a newsletter and has an online forum via the website.

The Kidney Cancer Support Network
c/o The Bungalow, West Cliff, Porthtowan, Nr Truro TR4 8AE
Tel 01209 890 326 (Mon–Fri, 10am–4pm)
Email team@kidneycancer supportnetwork.co.uk
www.kidneycancer supportnetwork.co.uk
Helps kidney cancer patients, families and friends join together and offer information, advice and friendship to each other.

General cancer support organisations

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

**Cancer Support Scotland**  
Shelley Court,  
Gartnavel Complex,  
Glasgow G12 0YN  
**Tel** 0141 211 0122  
**Email** info@cancersupportscotland.org  
[www.cancersupportscotland.org](http://www.cancersupportscotland.org)  
Offers information and support to people affected by cancer.  
Also runs support groups, and provides counselling and complementary therapies.

**Irish Cancer Society**  
43–45 Northumberland Road,  
Dublin 4, Ireland  
**Tel** 1800 200 700  
(Mon–Thurs, 9am–7pm, Fri, 9am–5pm)  
**Email** helpline@irishcancer.ie  
[www.cancer.ie](http://www.cancer.ie)  
Has a freephone cancer helpline staffed by nurses trained in cancer care.

You can also chat to a nurse online and use the site’s message board.

**Maggie’s Centres**  
1st Floor, One Waterloo Street,  
Glasgow G2 6AY  
**Tel** 0300 123 1801  
**Email** enquiries@maggiescentres.org  
[www.maggiescentres.org](http://www.maggiescentres.org)  
Maggie’s Centres provide information about cancer, benefits advice, and emotional or psychological support.

**Marie Curie Cancer Care**  
89 Albert Embankment,  
London SE1 7TP  
**Tel** 0800 716 146  
(Mon–Fri, 9am–5.30pm)  
**Email** supporter.services@mariecurie.org.uk  
[www.mariecurie.org.uk](http://www.mariecurie.org.uk)  
Marie Curie nurses provide free end-of-life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.
Tenovus
Head Office,
Gleider House, Ty Glas Road,
Cardiff CF14 5BD
Tel 0808 808 1010
www.tenovus.org.uk
Provides a range of services to people with cancer and their families, including counselling and a freephone helpline.

The Ulster Cancer Foundation
40–44 Eglantine Avenue,
Belfast BT9 6DX
Freephone helpline
0800 783 3339
Helpline email
infocis@ulstercancer.org
Tel 028 9066 3281
Email info@ulstercancer.org
www.ulstercancer.org
Provides a variety of services for people with cancer and their families, including a free telephone helpline, which is staffed by specially trained nurses with experience in cancer care.

Support for carers

Carers Trust (formerly Crossroads Care and The Princess Royal Trust for Carers)
32–36 Loman Street,
London SE1 0EH
Tel 0844 800 4361
Email info@carers.org
www.carers.org
Supports unpaid carers, giving them access to services such as respite care and information about how to manage being a carer. Also has national offices that provide local support in England, Scotland and Wales:

London office:
14 Bourne Court,
Southend Road,
Woodford Green IG8 8HD
Tel 0844 800 436

Glasgow office:
In Scotland, Carers Trust is known as The Princess Royal Trust for Carers.
Charles Oakley House,
125 West Regent Street,
Glasgow G2 2SD
Tel 0141 221 5066
Other useful organisations

**Cardiff office:**
3rd Floor, 33–35 Cathedral Road, Cardiff CF11 9HB
Tel 0292 009 0087

**Carers UK**
20 Great Dover Street, London SE1 4LX
Tel (England, Scotland, Wales) 0808 808 7777
Tel (Northern Ireland) 028 9043 9843
(Wed–Thurs, 10am–12pm and 2–4pm)
Email adviceline@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.

**Financial or legal advice and information**

**Benefit Enquiry Line**
(England, Scotland, Wales)
Warbreck House, Warbreck Hill Road, Blackpool FY2 0YE
Tel 0800 882 200 (Mon–Fri, 8.30am–6.30pm)

**Email** BEL-Customer-Services@dwp.gsi.gov.uk
www.gov.uk/browse/benefits/disability
Provides advice and information for disabled people and carers on the range of benefits available.

**NI Direct**
(Northern Ireland)
Tel 0800 220 674
www.nidirect.gov.uk/money-tax-and-benefits

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

**England and Wales**
www.citizensadvice.org.uk

**Scotland**
www.cas.org.uk

**Northern Ireland**
www.citizensadvice.co.uk
You can also find advice online in a range of languages at adviceguide.org.uk

**Personal Finance Society – ‘Find an Adviser’ service**
42–48 High Road, South Woodford, London E18 2JP
**Tel** 020 8530 0852
**www.findanadviser.org**

Use the website to find qualified financial advisers in your area.

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**Further resources**

- Cancer and complementary therapies
- Eating problems and cancer
- Eating well after cancer treatment
- Getting travel insurance
- Giving up smoking
- Healthy eating and cancer
- Hello, and how are you?
- Help with the cost of cancer
- How are you feeling? The emotional effects of cancer
- Insurance
- Life after cancer treatment
- Lost for words: how to talk to someone with cancer
- Making treatment decisions
- Physical activity and cancer treatment
- Self-employment and cancer
• Talking about your cancer
• Talking to children when an adult has cancer
• Understanding cancer research trials (clinical trials)
• Understanding chemotherapy
• Understanding radiotherapy
• Understanding secondary cancer in the bone
• Weight management after cancer treatment
• Work and cancer
• Working while caring for someone with cancer

To order these or any of our fact sheets, visit be.macmillan.org.uk or call 0808 808 00 00. Our information is also available at macmillan.org.uk/cancerinformation

Audio resources

Our high-quality audio materials, based on our variety of booklets, include information about cancer types, different treatments and about living with cancer.

To order your free CD, visit be.macmillan.org.uk or call 0808 808 00 00.

Useful websites

A lot of information about cancer is available online. Some websites are excellent; others are misleading or out-of-date. The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

Macmillan Cancer Support www.macmillan.org.uk

Find out more about living with the practical, emotional and financial effects of cancer. Our website contains expert, accurate, up-to-date information about cancer and its treatments, including:

• all the information from our 150+ booklets and 360+ fact sheets
• videos featuring real-life stories from people affected by cancer and information from medical professionals
Understanding kidney cancer

- how Macmillan can help, the services we offer and where to get support
- how to contact our cancer support specialists, including an email form to send your questions
- local support groups search, links to other cancer organisations and a directory of information materials
- a huge online community of people affected by cancer sharing their experiences, advice and support.

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

**www.cancer.org**
(American Cancer Society)
Nationwide community-based health organisation dedicated to eliminating cancer. It aims to do this through research, education and advocacy.

**www.cancerhelp.org.uk**
(Cancer Research UK)
Contains patient information on all types of cancer and has a clinical trials database.

**www.healthtalkonline.org**
**www.youthhealthtalk.org**
(site for young people)
Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

**www.macmillan.org.uk/cancervoices**
(Macmillan Cancer Voices)
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.

**www.nhs.uk**
(NHS Choices)
NHS Choices is the online ‘front door’ to the NHS. It is the country’s biggest health website and gives all the information you need to make decisions about your health.
Further resources

www.nhsdirect.nhs.uk (NHS Direct Online)
NHS health information site for England – covers all aspects of health, illness and treatments.

www.nhs24.com (NHS 24 in Scotland)

www.nhsdirect.wales.nhs.uk (NHS Direct Wales)

www.n-i.nhs.uk (Health and Social Care in Northern Ireland)

www.patient.co.uk (Patient UK)
Provides people in the UK with good-quality 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.

www.riprap.org.uk (Riprap)
Developed especially for teenagers who have a parent with cancer.
Your notes and questions

You could use this page to write down any questions you want to ask your doctor or nurse, and then to write down the answers you receive.
Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photographs are of models.

Thanks

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With thanks to: Dr Rosalie Fisher, Clinical Research Fellow; Dr James Larkin, Consultant in Oncology; Dr Louise Lim, Medical Oncology Registrar; Dr Vinod Nargund, Consultant Urological Surgeon; Debbie Victor, Uro-Oncology Clinical Nurse Specialist; and the people affected by cancer who reviewed this edition.

Sources

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


Can you do something to help?

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

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

5 WAYS YOU CAN HELP SOMEONE WITH CANCER

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

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

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

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

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

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

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

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

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro
Card number
Valid from
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
Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That's who we are.

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

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

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

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.