

**MACMILLAN**  
CANCER SUPPORT

# UNDERSTANDING KIDNEY CANCER





After the operation, because I only work part-time I was not entitled to sick pay. Macmillan helped me find out what I could be entitled to. They were really helpful and very nice.

Eileen, diagnosed with kidney cancer.

# About this booklet

This booklet is about a type of kidney cancer called renal cell cancer. It is for anyone who has been diagnosed with kidney cancer, or is having tests for it. There is also information for carers, family members and friends.

The booklet explains how renal cell cancer is diagnosed and treated. The booklet also talks about your feelings when you are diagnosed with cancer. You can find practical advice on dealing with work and finances towards the end of the booklet.

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

There is another type of cancer that can affect the kidney. This is called cancer of the ureter and renal pelvis (or urothelial cancer). It is sometimes called transitional cell cancer. Doctors treat it in a different way to renal cell cancer. We have separate information about this on our website [macmillan.org.uk](http://macmillan.org.uk).

Rarely, very young children and adults develop a type of kidney cancer called Wilms' tumour (or nephroblastoma). The Children's Cancer and Leukaemia Group (CCLG) have an information sheet about Wilms' tumour that is available on our website.

## For more information

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

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

## How to use this booklet

The booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

In this booklet, we have included quotes from people who have had kidney cancer, which you may find helpful. This includes Eileen, who is on the cover of this booklet. Some quotes are from our Online Community (**community.macmillan.org.uk**). Others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

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# ABOUT KIDNEY CANCER

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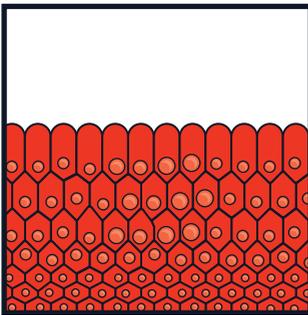
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# What is cancer?

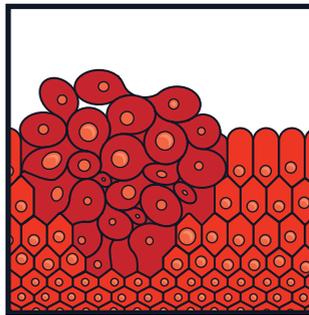
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop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

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

Normal cells



Cells forming a tumour



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

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see pages 8 to 9). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

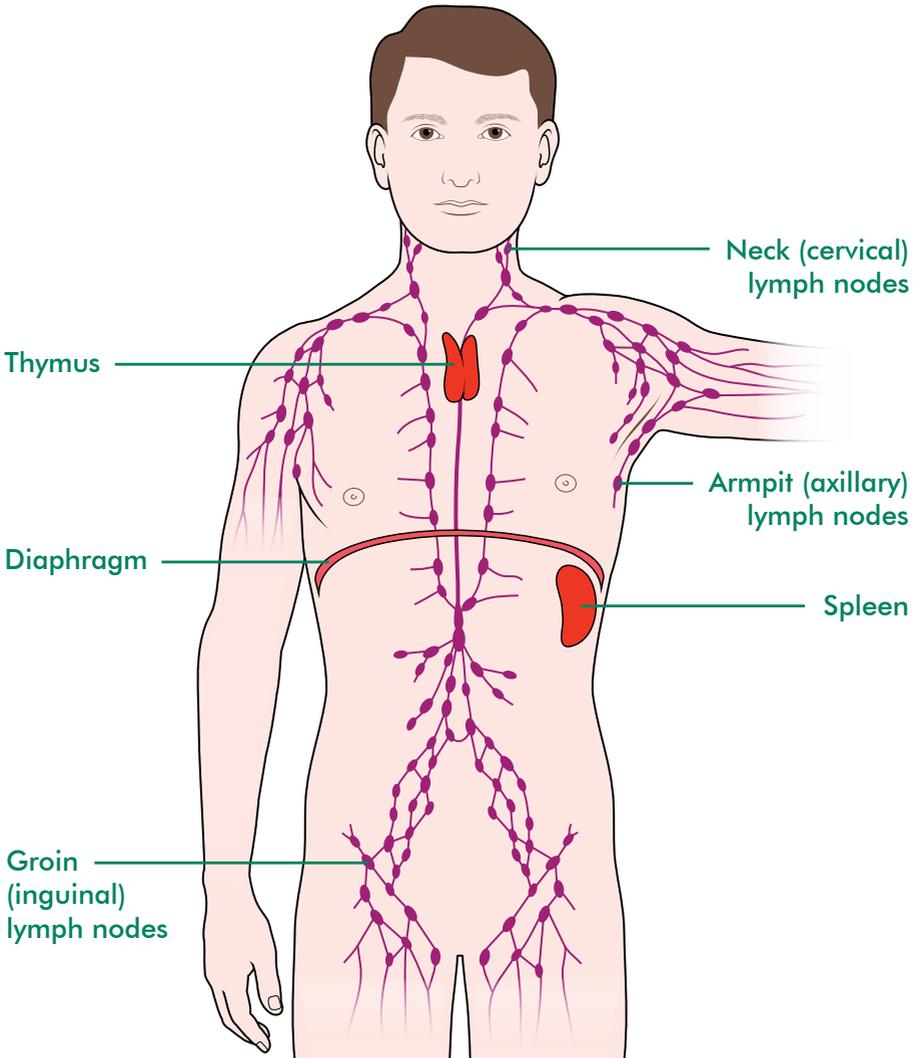
# The lymphatic system

The lymphatic system helps 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 kidney cancer can spread to lymph nodes close to the kidney (see page 13).

## The lymphatic system



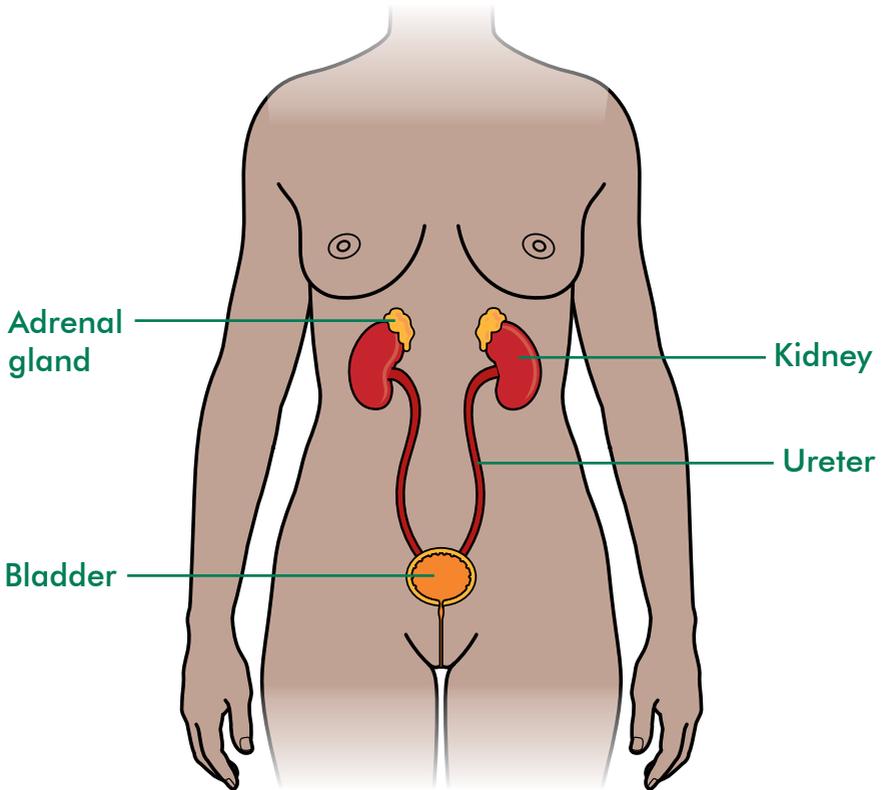
# The kidneys

Most people have two kidneys. They are at the back of the body. One is on each side of the back bone (spine), just underneath the ribcage.

The kidneys are part of the urinary system. The kidneys filter the blood to remove excess water and waste products. These are then made into urine (pee).

On top of each kidney, there is a small gland called the adrenal gland (see the illustration opposite). This makes hormones. The kidneys and adrenal glands are surrounded by a layer of fat, contained in a capsule of fibrous tissue (see the illustration on page 13).

## The kidneys in the body



## How the kidneys work

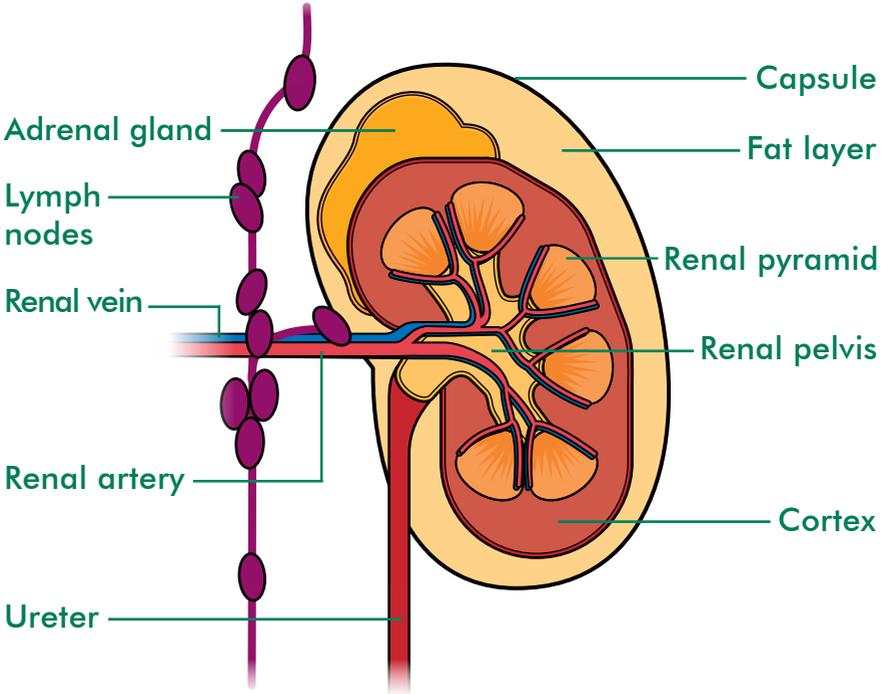
The kidneys clean the blood and keep anything the body needs. This helps control the balance of fluid, salt and minerals in the body. It also helps maintain blood pressure.

Blood goes to the kidney through a large blood vessel called the renal artery. Inside the kidney there are millions of tiny filters, called nephrons. The nephrons start in the part of the kidney called the cortex and extend into triangle-shaped areas called renal pyramids.

The nephrons filter the blood to remove waste products and any extra water, which are made into urine (pee). The 'clean' filtered blood goes back to the rest of the body through the renal vein.

The urine collects in an area in the middle of each kidney. This area is called the renal pelvis. Urine then drains from each kidney through a long muscular tube called a ureter. There are two ureters – one from each kidney. The ureters connect to the bladder, where urine is stored before being passed out of the body (see the illustration on page 11).

## The structure of the kidney



# Kidney cancer

Each year, over 12,500 people in the UK are diagnosed with kidney cancer. Kidney cancer usually only affects one kidney. It is very uncommon for cancer to be in both kidneys.

## Types of kidney cancer

There are different types of kidney cancer. About 8 out of 10 kidney cancers (80%) are renal cell cancers (RCC). They start in the cortex of the kidney (see the illustration on page 13).

There are different types of RCC. The most common type is clear cell renal cancer. Less common types are:

- papillary renal cell cancer
- chromophobe renal cell cancer.

Kidney cancer can also start in the renal pelvis. This is usually a type of cancer called urothelial cancer or transitional cell carcinoma. We have separate information about the treatment of cancer in the renal pelvis on our website (see page 104).

Another rare type of kidney cancer is called collecting duct cancer (CDC). This cancer has features of both RCC and of urothelial cancer. Your doctor can give you more information about CDC.

# 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 does not necessarily mean you will get kidney cancer, and people without risk factors can also develop cancer.

## Gender

Kidney cancer is more common in men than women.

## Age

The risk of kidney cancer increases with age. Most people who get kidney cancer are over 60, although it can affect people younger than this.

## Smoking

Smoking increases the risk of developing kidney cancer. The more a person smokes, the greater their risk.

Risk goes down when a person stops smoking. After 10 years, it returns to the same as a non-smoker.

## Being overweight

Studies show that being overweight (obese) increases the risk of getting kidney cancer.

## High blood pressure

Having high blood pressure may slightly increase the risk of kidney cancer. But most people with high blood pressure do not develop kidney cancer.

## Kidney disease

People with advanced kidney disease have a higher risk of developing kidney cancer. The risk is greatest for people who need treatment to do the work of the kidneys (dialysis).

## Family history

Most people who get kidney cancers do not have a family history of it. But your risk may be higher than average if a close relative has had kidney cancer. Close relatives are your parents, brothers, sisters or children. Fewer than 1 in 20 kidney cancers (4%) are thought to be inherited.

## Genetic risk

Some rare genetic conditions can increase the risk of developing kidney cancer. These include:

- von Hippel-Lindau disease
- hereditary papillary RCC (HPRCC)
- Birt-Hogg-Dubé (BHD) syndrome
- tuberous sclerosis.

Kidney cancers caused by an inherited gene change are more likely to happen at a younger age. They may cause several tumours, and can affect both kidneys.

## Exposure to certain materials at work

An increased risk of kidney cancer has been linked to working with blast furnaces or coke ovens in the steel and coal industries. Exposure to certain materials may also increase risk, such as those used in heavy engineering. These include:

- cadmium
- lead
- asbestos
- trichloroethylene (Tric).

Cancer is not contagious and you cannot pass it on to other people.

'I had lost a lot of weight but I was actually eating just as much as before. I was very tired as well, but I was working full-time, so it was easy to put it down to that. My back had also been sore, but I thought nothing of it.'

Eileen



# Signs and symptoms

Small kidney cancers do not usually cause symptoms. They are often diagnosed by chance. For example, they may be diagnosed when people are having tests or scans for another reason.

When kidney cancer does cause symptoms, the most common symptom is blood in the urine (pee). Other symptoms may include:

- a dull pain in your side, between the upper abdomen (the top of the tummy) and back
- a high temperature (fever) or night sweats
- feeling very tired (fatigue)
- losing weight for no obvious reason
- loss of appetite
- a lump in your side or back.

Most people with these symptoms do not have kidney cancer. These symptoms can be caused by more common conditions. But if you have any symptoms, it is important to get them checked by your doctor.



# DIAGNOSING KIDNEY CANCER

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# How kidney cancer is diagnosed

Sometimes kidney cancer is diagnosed when a person is having a scan for another reason.

If you have symptoms, you usually start by seeing your GP. They will examine you and arrange for you to have some tests. They may test your urine (pee). They may also do blood tests to check:

- your general health
- the number of cells in your blood (blood count)
- how well your kidneys and liver are working.

If your GP is not sure what the problem is or they think your symptoms could be caused by cancer, they will usually refer you to the hospital to see a specialist doctor. This doctor is called a urologist. They specialise in treating urinary, bladder and kidney problems.

If you have blood in your urine, you may be referred to a specialist clinic. This is called a haematuria clinic. Often these clinics can do tests on the same day.

If tests or symptoms suggest you could have a kidney cancer, you should be seen by a specialist within 2 weeks.

## At the hospital

The urologist or specialist nurse will ask you about your symptoms and your general health. They will also examine you and arrange some of the following tests.

## Blood tests

You will have blood samples taken. These help your doctors check how well your kidneys and liver are working. They also show the number of blood cells in your blood. This is called a blood count.

## Ultrasound scan

This test uses sound-waves to build up a picture of the kidneys, ureters and bladder (see the illustration on page 11). It is a painless test and only takes a few minutes.

You lie on your back and the person doing the ultrasound spreads gel over your tummy (abdomen) area. They pass a small, hand-held device that produces sound-waves over your tummy. A computer turns the sound-waves into a picture.

If doctors also want to look at the bladder, you will need to have a full bladder for the scan. The hospital will give you instructions about this.

The ultrasound scan can look for changes in the shape of the kidneys. It can help show whether a lump is a cyst (a fluid-filled lump) or a tumour. It can also show the position of a cancer and its size.

## CT urogram

A CT urogram is a type of CT scan. It looks at the kidneys, ureters and bladder.

A CT scan takes a series of x-rays that build up a three-dimensional picture of the inside of the body. The scan is painless and takes about 60 minutes (1 hour). CT scans use 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 given instructions on how to prepare for the test. Before the test, you can usually eat and drink normally. Just before the test you may be asked to empty your bladder.

You will be given an injection of a dye. This helps the doctor see your bladder, ureters and kidneys more clearly. The dye may make you feel hot all over for a few minutes. Some people have a stronger reaction to the dye. Tell your doctor if you have asthma or an iodine allergy, because you could have a stronger reaction to the injection. You should also tell your doctor if you have kidney problems or diabetes, particularly if you take metformin. You will need a blood test before the scan to check how well your kidneys are working. We have more information about cancer and diabetes (see page 104).

The dye travels through the bloodstream to the kidneys. The doctor looks at a screen to see the dye passing through the kidneys and ureters.

You should be able to go home as soon as the scan is over.

## **Guided biopsy**

This is done if you need to have a sample of tissue taken from the kidney (a biopsy). The doctor uses ultrasound or a CT scan to guide them to the exact area of kidney they want to take the biopsy from.

The doctor injects some local anaesthetic into the skin to numb the area over the kidney. They then guide the needle through the skin into the kidney. They use the needle to take a small sample of tissue. They send the sample to the laboratory to be checked for cancer cells.

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

## Further tests

If the tests show you have kidney cancer, your doctor may want to do some further tests. These tests will help them find out the size and position of the cancer and whether it has spread to other parts of the body. This is called staging (see pages 28 to 32) and will help you and your doctor decide on the best treatment for you. These may include some of the following tests.

### CT 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 to 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 is 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 will probably be able to go home as soon as the scan is over.

We have included a picture of what a CT scan looks like on page 27.

## **MRI scan**

Some people have an MRI scan instead of, or as well as, a CT 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 is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc.

You should also tell your doctor if you have 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 is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which does not 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 will lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you will be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

## **Chest x-ray**

If you do not have a CT scan of the chest, you will have a chest x-ray to check the health of your lungs.

## 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, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 109 to 115 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

### Having a CT scan



# Staging and grading

Your cancer doctor needs certain information about the cancer to advise you on the best treatment for you. This includes the following:

- The stage of the cancer, which describes its size and whether it has spread.
- The grade of the cancer, which gives an idea of how quickly the cancer might grow and spread (see page 32).

This information comes from the tests you have had.

Your cancer doctor and specialist nurse will talk to you about this. They will explain how it helps you and your doctor decide on your treatment plan.

## **T** **N** **M** staging

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).

## T Tumour

- T1 means the cancer is only inside the kidney and is no bigger than 7cm.
  - T1a – The cancer is 4cm or smaller.
  - T1b – The cancer is bigger than 4cm.
- T2 means the cancer is only inside the kidney and is bigger than 7cm.
  - T2a – The cancer is between 7cm and 10cm.
  - T2b – The cancer is bigger than 10cm.
- T3 means the cancer is growing into the fat around the kidney or into a major vein (the renal vein and vena cava) close to the kidney. It is not growing outside the capsule that surrounds the kidney (see the illustration on page 13).
  - T3a – The cancer is growing into the fat around the kidney or into the renal vein.
  - T3b – The cancer is growing into the vena cava in the tummy (abdomen).
  - T3c – The cancer is growing into the vena cava in the chest or into the wall of the vena cava.
- T4 means the cancer has spread through the capsule that surrounds the kidney. It may have grown into the adrenal gland (see the illustration on page 13).

## **N** Nodes

- N0 means there are no cancer cells in any lymph nodes.
- N1 means there are cancer cells in one or more of the lymph nodes.

If the cancer cells have spread to the lymph nodes, doctors will say the nodes are positive.

## **M** Metastasis

- M0 means the cancer has not spread to other parts of the body further away from the kidney.
- M1 means the cancer has spread to parts of the body further away from the kidney, such as the bones, lungs, liver or brain. If the cancer has spread, it is called secondary or metastatic kidney cancer.

‘When you’re first diagnosed, it cuts your feet out from under you and it’s difficult to see any future. But as things improve, you realise you can still enjoy yourself.’

**Ian**

## Number staging

This system brings together information from the TNM stages and gives the cancer a number stage. These range from stages 1 to 4.

### Stage 1

The cancer is 7cm or smaller and is inside the kidney. It has not spread to the lymph nodes or other organs.

### Stage 2

The cancer is bigger than 7cm and is inside the kidney. It has not spread to the lymph nodes or other organs.

### Stage 3

The cancer is growing into the fat around the kidney or into one of the major veins close to the kidney (the renal vein or the vena cava). It is not growing through the capsule that surrounds the kidney. It may have spread to the lymph nodes, or it may not.

### Stage 4

The cancer has grown through the capsule that surrounds the kidney. It may have spread to the lymph nodes, but not to other parts of the body further away from the kidney.

Or the cancer can be any size and may have grown through the capsule surrounding the kidney, and spread to other parts of the body further away from the kidney.

## Other terms used

Your doctor may use other terms to describe the stage of the cancer:

- **Early** or **local** may be used to describe a cancer that has not spread.
- **Locally advanced** describes a cancer that has begun to spread into surrounding tissues or nearby lymph nodes.
- **Local recurrence** means the cancer has come back in the same area after treatment.
- **Secondary, advanced** or **metastatic** means the cancer has spread to other parts of the body.

## Grading

A doctor decides the grade of the cancer by looking at the cancer cells under a microscope. The grade gives an idea of how the cancer might grow or spread.

Kidney cancers are usually given a grade from 1 to 4. This is called the Fuhrman system. The lower the number, the lower the grade.

- Low-grade means the cancer cells are more like normal cells. Grade 1 and 2 cancer cells are slow-growing and less likely to spread.
- High-grade means the cancer cells are less like normal cells. Grade 3 and 4 cancer cells grow more quickly and are more likely to spread.

# Your data and the cancer registry

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

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



# TREATING KIDNEY CANCER

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# Treatment overview

Treatment depends on a number of factors, including the position, type, stage and grade of the cancer (see pages 28 to 32). Your doctors will also consider how well your kidneys work, your general health and your personal preferences.

Research is going on to find more effective treatments for kidney cancer. You may be invited to take part in a clinical trial for a new drug or treatment (see pages 74 to 75).

## Early kidney cancer

Early kidney cancer that has not spread outside the kidney (stage 1 or stage 2) is usually treated with surgery (see pages 43 to 53). If the cancer is small, the surgeon will usually only remove the part of the kidney containing the cancer. But if the cancer is bigger, they may need to remove the whole kidney. They sometimes do this using keyhole surgery (see pages 46 to 47). Surgery may be the only treatment needed.

In some situations, treatments that destroy the cancer cells with very high or low temperatures are used to treat small kidney cancers. This is called tumour ablation (see pages 54 to 59). It may be used instead of surgery.

Some kidney cancers are slow-growing and very unlikely to spread outside the kidney. In certain situations, people who have small kidney cancers (less than 3cm across) may not need treatment. Instead, they have regular scans of their kidneys to monitor the cancer. If the cancer shows signs of growing, they can have treatment. This approach is called monitoring or active surveillance (see pages 64 to 65).

## Locally advanced kidney cancer

If the cancer is bigger, or has spread to lymph nodes but not to other parts of the body, surgery is often the main treatment. Targeted therapy and immunotherapy drugs may be used to reduce the risk of the cancer coming back after surgery (see pages 66 to 72). They may be used as part of a clinical trial.

## Advanced (metastatic or secondary) kidney cancer

Targeted therapy drugs are the main treatment for advanced kidney cancer. Immunotherapy may also be used (see pages 71 to 72). These treatments are used to try to control the cancer. This can help to improve symptoms and quality of life.

If the cancer has spread outside the kidney to other parts of the body, your surgeon may still advise you to have surgery to remove the kidney. If an operation is possible, it will usually be combined with other treatments, such as targeted therapy.

Sometimes surgery is used to remove a secondary cancer, for example in the lung. This is not common. But it may be done if there is only one area of secondary cancer and no sign of cancer elsewhere.

Some advanced kidney cancers that are low-grade may grow very slowly. In this situation and if the cancer is not causing symptoms, your specialist may suggest monitoring the cancer with scans for a while before starting treatment (see pages 64 to 65).

Chemotherapy is not a standard treatment for kidney cancer. But it is sometimes used to treat advanced urothelial cancer of the kidney. Occasionally, radiotherapy is used to relieve symptoms caused by advanced kidney cancer (see page 73).

## How your treatment is planned

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

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

It may also include other healthcare professionals, such as a dietitian, a physiotherapist, an occupational therapist (OT), a psychologist or a palliative care specialist.

## Treatment decisions

Your cancer doctor and specialist nurse will talk to you about your treatment options. They will know what the most effective treatments are, but you know your lifestyle and preferences. They will explain the options available, and they can help you if you need to make decisions about treatment. Research into kidney cancer is going on all the time. Your specialist may ask you if you would like to take part in a clinical trial.

If you have to decide between treatments, make sure you understand what each treatment involves and any possible side effects.

If you have any questions about your treatment, ask your doctor or nurse.

You may find it useful to write down a list of your questions before meeting with your doctor or nurse. You can use the space on pages 116 to 117 to do this. If you can, it might help to bring a partner, family member or friend with you to meetings. They can help you remember what was said.

If you feel you cannot make a decision when your treatment is first explained to you, you can always ask for more time. If there is anything you do not understand, ask your doctor or nurse to explain it again. Cancer treatments can be complicated. It is also hard to take things in when you are feeling anxious. You may need to have more than one meeting with your doctor about your treatment.

## **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 upon your individual situation.

If you have been offered treatment that aims to cure the cancer, it may be easy to decide whether to accept the treatment. However, if a cure is not possible or less likely it may be more difficult to decide whether to go ahead.

Making decisions about treatment in these circumstances is always difficult. You may need to talk in detail with your doctor about 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.

## 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 do not understand what you have been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it is not unusual to need repeated explanations. It is 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 is 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 do not have it. It is essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes.

You do not 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.

## 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.



**'They told me I needed surgery. I knew it would be a hard surgery as the lump was near major blood vessels.'**

**Eileen**

# Surgery

Surgery may be the only treatment you need. The type of operation you have will depend on the stage of the cancer (see pages 28 to 32) and on your general health. It is important to talk to your surgeon and specialist nurse about the operation before you have it.

## Removing part of the kidney

This is the most common operation for cancers that are smaller than 4cm. But it may sometimes be done for bigger cancers.

The surgeon removes only the part of the kidney with the cancer. This is called a partial nephrectomy or kidney-sparing surgery. The aim is to remove the cancer, and to leave you with as much normal kidney tissue as possible. This is so the kidney can still work.

Kidney-sparing surgery may also be done if it is important to try to keep the affected kidney. For example, this might happen if you have only one working kidney or have kidney disease. If you have an inherited type of kidney cancer, you may be offered this operation. This is because there is a risk you could develop a cancer in the other kidney. You may be referred to a specialist hospital for this type of surgery. This may mean you have to travel for treatment.

## Removing the whole kidney (nephrectomy)

This is when the surgeon removes the whole kidney and some surrounding tissue. This is called a radical nephrectomy. Your surgeon may also remove lymph nodes close to the kidney (see the illustration on page 13) to check them for cancer cells.

You can live a normal life with one kidney. It will be able to do the work of both kidneys. Removing a kidney is a big operation and is not suitable for everyone. Your doctors may need to do tests to check you are fit enough to cope with the surgery.

If there is cancer in one of the large blood vessels leaving the kidney, it may be possible to have an operation to remove it. But this is a more complicated operation. You will need to go to a specialist hospital for this surgery.

## Removing the kidney when the cancer has spread

If the cancer has already spread to other places in the body, your surgeon may still suggest removing the kidney. This will not usually cure the cancer, but it can help some people live longer. It may help other treatments work better and reduce cancer symptoms.

You need to consider the possible advantages of having the kidney removed as well as the effects of having a big operation. Your doctors will talk to you about the possible benefits and disadvantages.

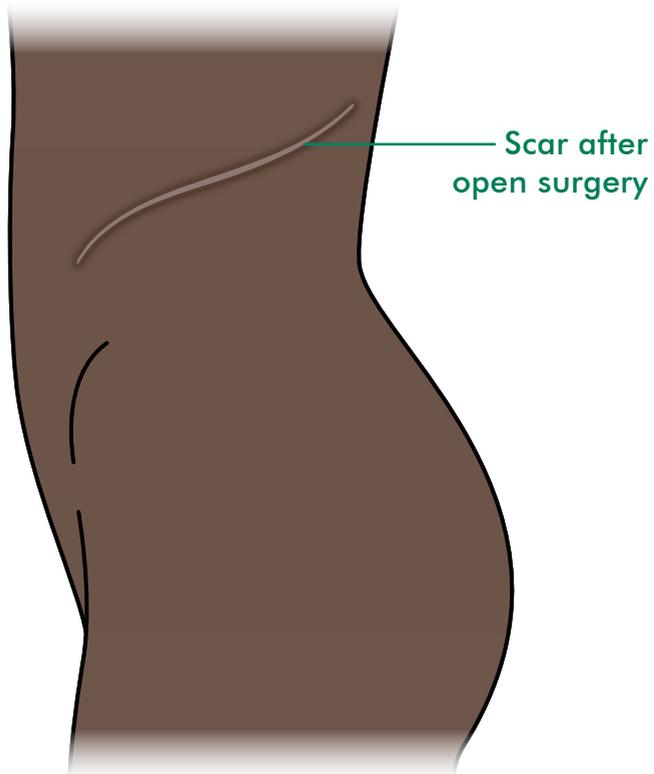
## Open, keyhole and robotic surgery

There are different ways a surgeon can operate on the kidney. Your surgeon will explain how they will do your operation and answer any questions you have.

### Open surgery

The surgeon makes one large cut (incision) just under the bottom rib or between the two bottom ribs. This cut can be up to 30cm long. After the operation, the surgeon stitches or staples the wound closed.

### Open surgery scar



## **Keyhole (laparoscopic) surgery**

The surgeon makes two or three small cuts and one larger cut.

They use a laparoscope to see and work inside the tummy (abdomen). The laparoscope is a thin tube with a light and a camera. It sends video images to a monitor.

The surgeon puts the laparoscope into the abdomen through one of the small cuts in the skin. They usually make a larger cut close to the belly button. They usually remove the kidney through this cut. The position of the cuts may vary from person to person. Your surgeon can talk to you about this.

Recovery from keyhole surgery is usually quicker than recovery from open surgery. This is because the wound is smaller.

## **Robot-assisted surgery**

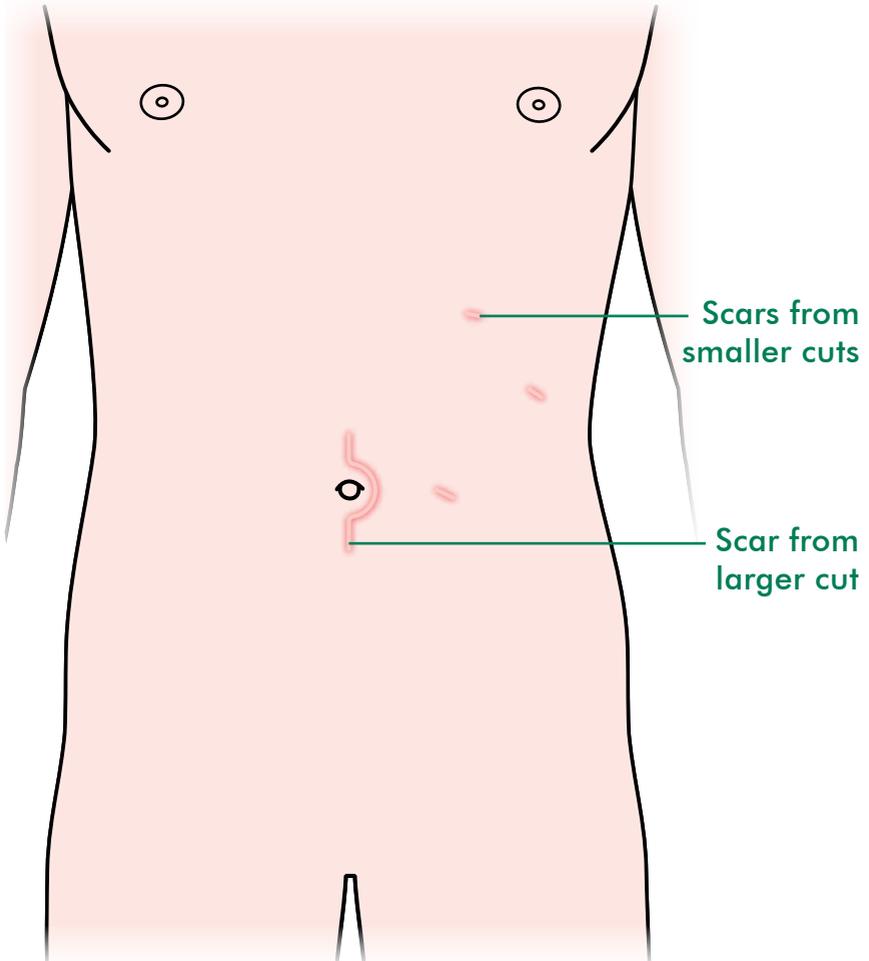
The surgeon may use a specialised machine to help with keyhole surgery. There are instruments attached to the machine, which the surgeon controls. This is called robot-assisted surgery. It makes it possible for the surgeon to do very precise surgery.

## **Surgery to remove a secondary cancer**

Rarely, an operation may be done to remove a secondary cancer in another part of the body. This is very specialised surgery. It is generally only possible if the cancer has spread to a limited area – usually just to one place in the body. It is also important that you are fit enough to cope with the operation.

Removing a secondary cancer may help control the cancer for longer. Occasionally, it may be used to try to cure the cancer.

## Keyhole surgery scars



## Before your operation

Before your operation, you will be seen at a pre-assessment clinic. You may have tests to check your general health. These can include:

- blood tests
- a chest x-ray
- a recording of your heart (ECG)
- tests to check your kidney function.

You will see a member of the surgical team and a specialist nurse. They will talk to you about your operation. This is a good time to ask questions or to talk over any concerns you may have about the operation. It is important that you understand everything about the operation you are having.

You will see the doctor who gives you your anaesthetic (the anaesthetist), either at a clinic or when you are admitted to hospital.

If you smoke, try to stop or cut down before your operation. This will help reduce your risk of chest problems, such as a chest infection. It will also help your wound heal after the operation. Your GP can give you advice and support to give up smoking. You may find our booklet **Giving up smoking** helpful (see page 104).

Some people may need help when they go home after surgery. For example, you may live alone or care for someone else. If you think you may need help when you go home, tell your healthcare team as soon as possible. This will mean arrangements can be made in plenty of time.

Some hospitals follow an enhanced recovery programme. This aims to reduce the time you spend in hospital and speed up your recovery. It involves you more in your own care. For example, you will be given information about diet and exercise before surgery. You may also be given supplement drinks to take.

You will usually be admitted to hospital the day before or on the morning of your operation. The nurses will give you elastic stockings (TED stockings) to wear during and after the operation. The stockings help prevent blood clots forming in the legs. Your doctor can tell you how long to wear them for.

## After your operation

Your recovery after surgery will depend on the type of operation you have.

After the operation, you will be encouraged to start moving around as soon as possible. This can help reduce the risk of some problems.

## Drips and drains

After your operation, you will have a drip going into a vein in the arm or neck (intravenous infusion). This will give you fluids until you are able to eat and drink again. It may also be used to give you painkillers and other medications. Once you are eating and drinking normally again, it is taken out.

You will usually have a tube (catheter) put in during the operation to drain urine (pee) from the bladder. This can be taken out a few hours after surgery. But some people may need it to stay in for longer. You may have a fine tube draining fluid and blood from the wound. It will drain into a small bottle. A nurse will take it out after a few days.

## Feeling sick (nausea)

Some people feel a bit sick for the first 24 hours after the operation. The nurse will give you anti-sickness injections or drugs to help control any sickness. If you still feel sick, tell your nurse.

## Pain and discomfort

You will have some pain and discomfort after your operation. This can be controlled with painkillers. For the first day or two after your operation, you will usually have one of the following:

- A pump attached to a needle in the arm. This gives painkillers into your bloodstream. You control the amount by pressing a button. This is called patient-controlled analgesia (PCA).
- An epidural. This gives painkillers directly into the spinal nerve system through a fine plastic tube in your back.

Before you go home, your pain will be controlled by tablets. You will be given a prescription for painkillers you can take at home as needed. You may still have some aches and twinges close to the scar for several weeks after surgery.

## Moving around

Moving around helps you recover more quickly. And it reduces the risk of complications.

The nurses will encourage you to get up fairly soon after your operation. The ward staff will help you with this. And you may need some help to wash and go to the toilet. Once you are moving about more freely, you will be able to do more for yourself.

Doing leg and breathing exercises can also help reduce the risk of chest infections and blood clots. Your nurse or physiotherapist will teach you these exercises.

You may be given a drug that helps prevent blood clots. This is called an anti-coagulant. A nurse will inject it under the skin, usually in the tummy (abdomen). The injections usually continue for 28 days. A nurse will show you, or a relative or friend, how to do the injection for when you go home. They will also give you advice about how to dispose of the needles safely. Sometimes a district nurse or practice nurse can give you the injections.

## Wound care

The wound is closed using staples or stitches. The staples are removed 7 to 10 days after the operation. This can be done by a practice nurse at your GP surgery. The stitches are usually dissolvable, so they do not need to be removed.

It is important to let your nurse or doctor know straight away if your wound:

- becomes hot or painful
- starts to bleed or leak any fluids.

'After surgery, you will have to take things slowly to build up your strength. This is doable. You will get through it. I was 61 when I had my operation and I know of others who are older, as well as younger, who have got through this.'

**Christine**

## Possible complications of surgery

The most common complications after surgery are:

- a wound infection
- bleeding
- a chest infection
- a blood clot.

The nurses will monitor you for these. Let them know straight away if you feel unwell, have any bleeding, or notice swelling and redness in a limb. You should also tell them if you have symptoms of an infection, such as a cough or discharge from your wound.

After open surgery to the kidney, some people develop a bulge along their scar. Doctors call this an incisional hernia. It can happen because of weakness in the muscles around the scar. Let your doctor or nurse know if you develop a bulge around the scar.

## Going home after surgery

How long you stay in hospital depends on the type of operation you have and how quickly you recover:

- After keyhole surgery, most people go home after 2 to 5 days.
- After an open operation, most people go home after 5 to 7 days.

It is common to feel more tired than usual for about 6 weeks after the operation. Most people feel fully recovered after about 12 weeks.

Your surgeon or nurse can tell you when you will be able to get back to doing everyday activities like shopping, driving, having sex, playing sport or going to work. We have more information about going back to work on pages 96 to 97.

You may find our booklet **Life after cancer treatment** helpful (see page 104).

Before you leave hospital, you will be given an appointment for a check-up. This is usually about 6 weeks after your operation. It will be at an outpatient clinic. The appointment is a good time to talk about any problems you have after your operation.

'Recovery was a longer and harder process than I thought it would be. I wanted to start working again, and I tried to do that too early. I was impatient.'

**Peter**

# Tumour ablation

Tumour ablation means destroying the tumour (cancer). It is sometimes used to treat cancers smaller than 3 to 4cm.

This treatment may be used if you have a small tumour, and are not fit enough to have surgery or choose not to have it.

Tumour ablation preserves more of the kidney than kidney-sparing surgery (see page 43). So it may be used for people who have only one kidney. It can also be an option for people who have an inherited form of kidney cancer that causes multiple tumours, or if cancer is affecting both kidneys.



Tumour ablation generally causes fewer side effects and has a quicker recovery time than surgery for kidney cancer. But there is a slightly higher risk of some cancer remaining in the kidney. The benefits of avoiding surgery and sparing more of the kidney need to be balanced against this risk. Your cancer doctor will talk to you about the risks and benefits if this treatment is an option for you.

There are different methods for destroying the tumour. The two most commonly used treatments are:

- cryotherapy, which uses liquid nitrogen to freeze the tumour
- radiofrequency ablation (RFA), which uses an electric current to produce high temperatures to destroy the tumour.

Other methods of tumour ablation may be used in clinical trials (see pages 74 to 75). These include:

- microwave ablation
- laser ablation
- high-intensity focused ultrasound (HIFU).

Your cancer doctor or specialist nurse will talk to you about tumour ablation.

## How tumour ablation is done

The doctor or nurse will give you a sedative before the treatment. This will make you feel drowsy. They will also use a local anaesthetic to numb the area over the kidney. Some people may have the treatment under a general anaesthetic.

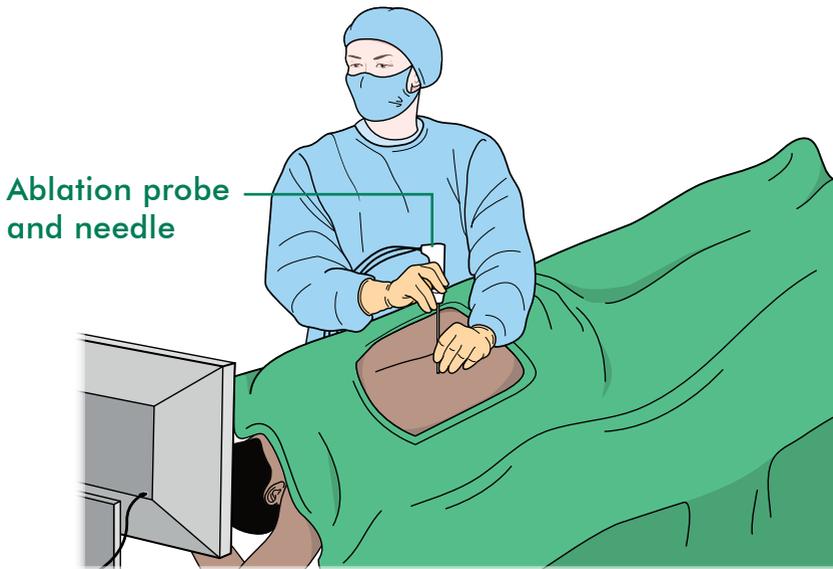
Next you will have an ultrasound or CT scan (see pages 23 and 25). These scans guide the doctor to the right area of the kidney.

The scans also help them monitor what is happening during your treatment. Sometimes the doctor will make a small cut and use a laparoscope to look inside the body. A laparoscope is a thin tube with a light and a camera that sends video images to a monitor.

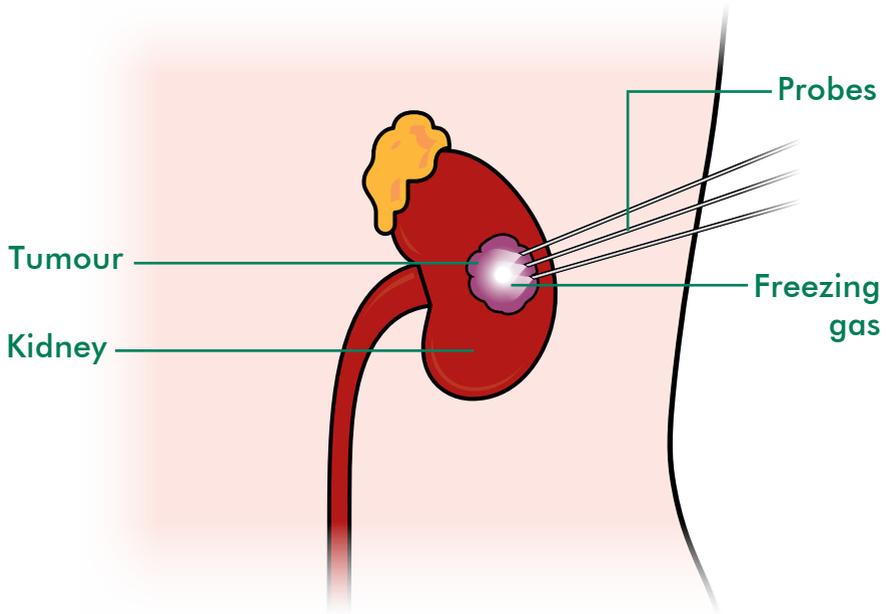
The doctor then places one or more fine probes through the skin (percutaneously) into the kidney, close to the tumour.

The probes freeze or heat the tumour. The extreme temperature destroys the cancer cells. The doctor will also aim to destroy a small area of healthy tissue (about 1cm) around the tumour. This is to try to make sure no cancer cells are left behind to grow back again.

## A surgeon performing tumour ablation



## Cryotherapy



### Side effects of tumour ablation

You will probably have some pain or discomfort at the treatment site. Your doctor will give you painkillers to take regularly for a few days.

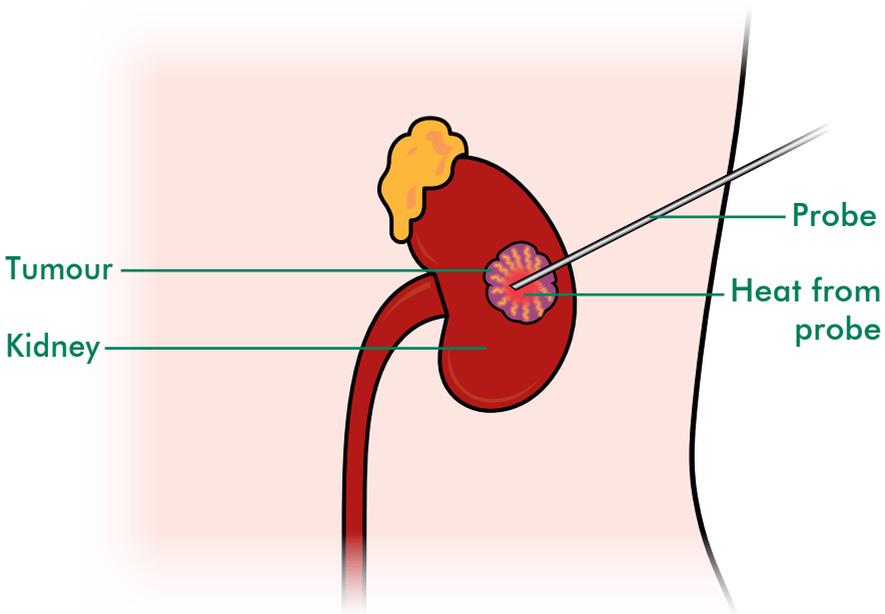
Sometimes people feel sick immediately after tumour ablation. If this happens, tell your nurse or doctor. They can give you anti-sickness drugs.

You may feel a little unwell for the first few days and have a slightly raised temperature. You will probably also feel tired. Drinking plenty of fluids will help. If your temperature does not return to normal, or if it goes above 38°C (100.4°F), contact your doctor, as this may be due to infection.

You may notice some blood in your urine (pee). This should disappear after a few days.

You usually stay in bed for 4 to 6 hours after the treatment. Most people go home the day after treatment and feel well enough to go back to their usual activities within a few days.

## Radiofrequency ablation



## Possible complications

The risk of complications after tumour ablation is low.

Possible complications include the following:

- Infection – you may be given antibiotics to reduce the risk of this happening.
- Bleeding – you will be monitored during the treatment and for a few hours afterwards.
- A narrowing of the tube connecting the kidney to the bladder (ureter). This can cause problems passing urine (peeing).

You will have a scan after treatment to check for any complications. These can be treated straight away if needed.

You will have regular follow-up scans to check the kidney for any signs of the cancer growing back.

**'I went through cryotherapy for kidney cancer two years ago and I'm doing great. No sign of tumour growth.'**

**Mary**

# Arterial embolisation

Arterial embolisation is when a substance is injected into a blood vessel (artery) in the kidney to block the blood supply to the cancer. This reduces the supply of oxygen and nutrients to the tumour, which can make it shrink or stop growing. It can help control symptoms, such as pain or bleeding.

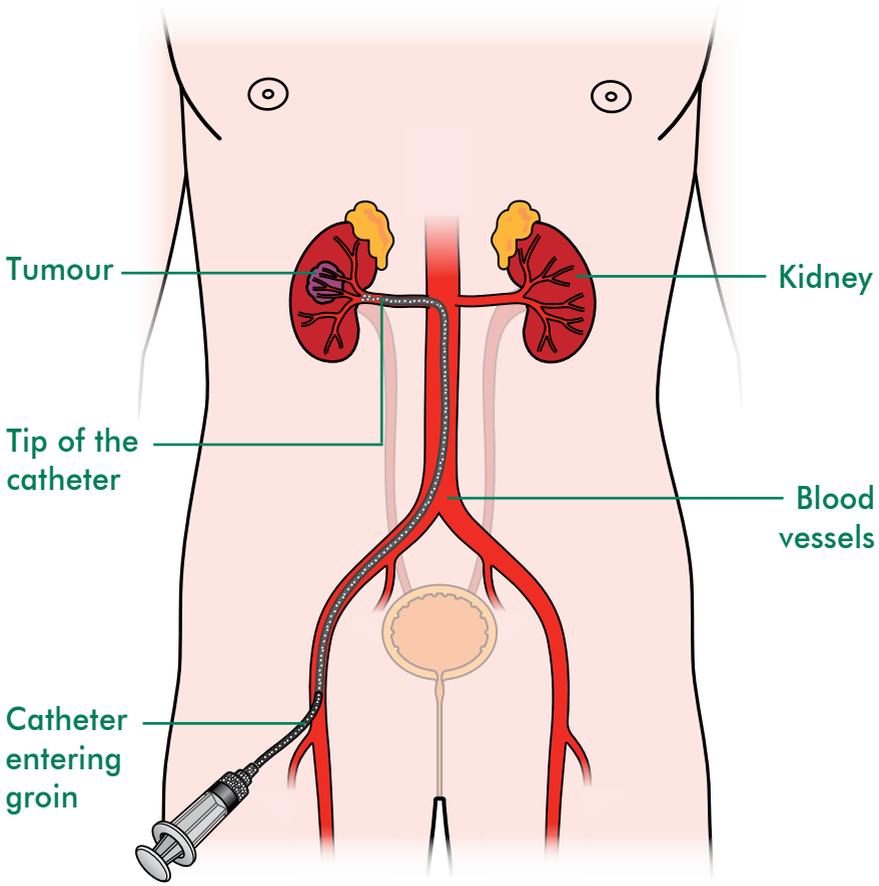
You may be offered tumour embolisation if an operation is not possible for you.

## How embolisation is done

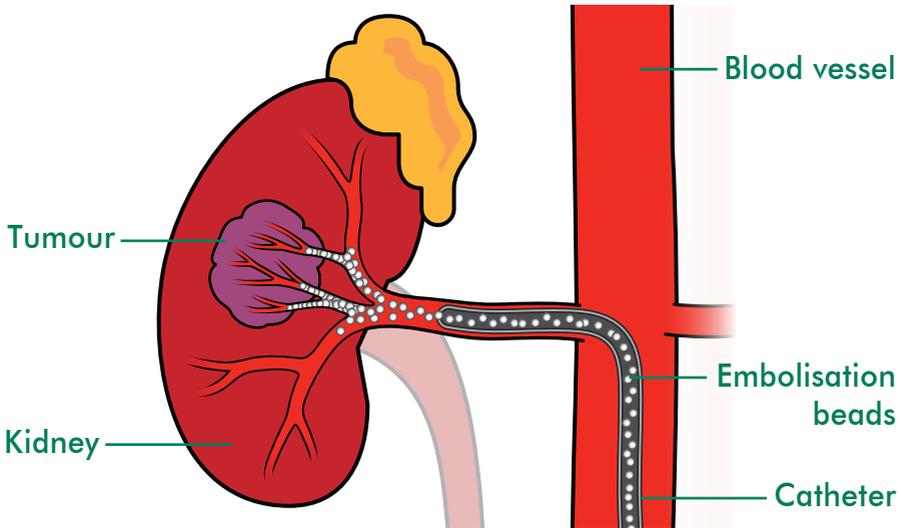
You may need to stay in hospital overnight, or possibly for a day or two longer. Before treatment, the nurse or doctor usually gives you a mild sedative to help you relax. They then inject some local anaesthetic into the skin at the top of the leg (the groin) to numb the area.

A doctor puts a thin, plastic tube (catheter) into a blood vessel in the groin (see the illustration opposite). Using x-ray pictures as a guide, they thread the catheter upwards until the tip is in the artery that carries blood to the area of the kidney where the cancer is. The doctor injects a substance, such as tiny beads, through the catheter into the artery, which blocks the blood supply to the cancer (see the illustration on page 62).

# Tumour embolisation



## Close-up of tumour embolisation



## Side effects of embolisation

This treatment can sometimes cause pain in the back. Your doctor will give you painkillers to take regularly for a few days.

You may feel a little unwell for the first few days and have a slightly raised temperature. You will probably also be tired.



# Monitoring

Kidney cancers vary a lot in how fast- or slow-growing they are. Some low-grade kidney cancers grow very slowly. See page 32 for information about grading.

Monitoring is an option for some people who have very small kidney cancers (less than 3cm). It is a way of delaying treatment until it is needed. It is most likely to be offered to people who already have health problems that would increase the risks of surgery. Because the cancer is slow-growing, it may not cause them any problems in their lifetime. Monitoring is sometimes called active surveillance.

Some people who have kidney cancer that has spread to other parts of the body but who do not have symptoms may also be offered monitoring before starting targeted therapy (see pages 66 to 70). Treatment will be started if monitoring shows the cancer is growing.

The main advantage of monitoring is that you will not experience the risks or side effects of treatment. If the size of the tumour or your symptoms change during monitoring, your cancer doctor or specialist nurse will talk to you about active treatment.

During monitoring, you will have regular ultrasound, CT or MRI scans (see pages 23 to 26). The scans will look for signs that the cancer is growing.

Before deciding whether monitoring is right for you, make sure you understand why it is recommended. If you have any concerns, talk to your cancer doctor.

Monitoring can be difficult to adjust to at first. You may find it difficult to accept that the cancer is not being treated. But many people find it gets easier as time goes on.

Sharing your feelings can help (see pages 86 to 90). As well as talking with family and friends, you may want to keep a journal, or join a support group. The Macmillan Online Community also has a kidney cancer group – visit [community.macmillan.org.uk](https://community.macmillan.org.uk)

'I joined an online group of fellow patients and it's great to chat to them. We all met for lunch for the first time and it was brilliant. It helped tremendously to talk to others who understand just how you feel.'

**Mary**

# Targeted therapies

Targeted therapies (also called biological therapies) interfere with the way that cancer cells grow. Some targeted therapies block (inhibit) signals in the cancer cells. Blocking the signals causes the cells to die. Some can also stop the cancer from making the new blood vessels, which it needs to grow.

Targeted therapy drugs are the main treatment for kidney cancer that has spread to other parts of the body (advanced or metastatic kidney cancer). The aim of treatment is to control the cancer for as long as possible.

There are several clinical trials looking at the most effective ways of using targeted therapies to treat kidney cancer (see pages 74 to 75).

Most targeted therapies for kidney cancer are taken as tablets. Others are given into a vein (intravenously). You usually have the treatment as an outpatient.

You will usually continue with a targeted therapy drug for as long as it is keeping the tumour under control. You will have regular CT scans to check this (see page 25). Some people may need to stop treatment or have a short break if they have very difficult side effects.

There are lots of different targeted therapy drugs. Not all of them are right for everyone. Your cancer doctor or specialist nurse will talk to you about the best drugs for your situation.

## Cancer growth inhibitors

For most people, the first targeted therapy drug given is usually a cancer growth inhibitor. Cancer growth inhibitors are also called TKIs (tyrosine kinase inhibitors). Kinases are proteins in the body. They regulate how cells grow and divide. TKIs block the proteins from sending signals within the cancer cells. This causes the cells to die. They can also stop the cancer cells from developing new blood vessels. This reduces their supply of oxygen and nutrients, so the tumour shrinks or stops growing.

The main cancer growth inhibitor drugs are:

- sunitinib (Sutent®)
- pazopanib (Votrient®)
- tivozanib (Fotivda®).

These drugs are taken as tablets.

Sunitinib is usually taken once a day for 4 weeks. This is followed by a 2 week rest period when you do not take the drug. This makes up a 6-week period called a treatment cycle. At the end of 6 weeks, the next cycle of treatment starts. Sometimes sunitinib is taken daily for 2 weeks followed by a 1-week rest period. This makes a 3-week cycle. You usually continue taking sunitinib for as long as it is working.

Pazopanib is usually taken once a day and is also given for as long as it is working.

Tivozanib is usually taken once a day for 3 weeks, followed by a 1-week rest period. The 4-week cycle of treatment is repeated for as long as it is working.

## Other targeted therapy drugs

Other targeted therapy drugs that may be used to treat advanced kidney cancer include:

- axitinib (Inlyta<sup>®</sup>) – this is given as a tablet
- cabozantinib (Cabometyx<sup>®</sup>) – this is given as a tablet
- everolimus (Afinitor<sup>®</sup>) – this is given as a tablet
- sorafenib (Nexavar<sup>®</sup>) – this is given as a tablet
- temsirolimus (Torisel<sup>®</sup>) – this is given into a vein (intravenously) as an infusion
- lenvatinib (Kisplyx<sup>®</sup>) – this is given as a capsule in combination with everolimus
- bevacizumab (Avastin<sup>®</sup>) – this is given into a vein as an infusion in combination with a drug called interferon alpha, which helps your immune system fight the cancer.

Your cancer doctor or specialist nurse will tell you if they think any of these drugs are suitable for you.

All the targeted therapy drugs listed here are licensed to treat kidney cancer and can be used in the UK. But not all of them are widely available through the NHS. Some people have targeted therapy as part of a clinical trial (see pages 74 to 75).

If a drug is not available on the NHS, there may be different ways you are still able to have it, if it is appropriate for you. Your doctor can give you advice. They may be able to apply for funding to get it.

## Side effects of targeted therapies

Each type of targeted therapy drug has its own side effects. The most common side effects include:

- tiredness
- diarrhoea
- skin rashes
- sore hands and feet
- sore mouth
- high blood pressure.

Your cancer doctor or specialist nurse will give you information about the likely side effects of your treatment. They will also tell you what can be done to control and manage side effects.

We have more information about side effects on our website (see page 104).

'I began to understand my side effects. I learnt to adapt and started to manage them better. Before I knew it, I was cooking dinners and doing chores again. I was feeling like myself.'

**Hollyann**

Targeted therapies can interact with some medicines and foods. Before you start treatment, tell your GP and cancer doctor about your treatment and any medicines you are taking. They can let you know if there are any foods you should avoid.

Let your cancer doctor and specialist nurse know if you are having problems. They can give you help and advice.

We have information about individual targeted therapy drugs, how they are given and their side effects (see page 104).



# Immunotherapies

Immunotherapy drugs encourage the body's immune system to fight cancer cells. These treatments are occasionally used to treat some types of advanced kidney cancer. Your specialist will tell you if they think any of these drugs are suitable for you.

There are many clinical trials looking at new immunotherapy drugs (see pages 74 to 75).

## Nivolumab (OPDIVO®)

Nivolumab belongs to a group of cancer drugs known as monoclonal antibodies. It is also known as an immune checkpoint inhibitor (ICI). It blocks a protein in the immune system called a checkpoint. Kidney cancer cells sometimes use checkpoint proteins to avoid being attacked by the immune system. So if the checkpoints are blocked, the immune system may attack and kill the cancer cells.

Nivolumab is given as a drip into a vein (intravenously) over about an hour. It can be given every 2 or 4 weeks for as long as it keeps the cancer under control.

Common side effects include:

- skin changes
- tiredness
- feeling sick
- diarrhoea
- high blood pressure.

It is important to tell your doctor or nurse about any side effects you have, even after you have stopped having nivolumab.

Nivolumab may not be widely available on the NHS for all types of kidney cancer. If a drug is not available, there may be different ways you can still have it. Your doctor can give you advice. They may be able to apply for funding to get it.

## **Ipilimumab (Yervoy®)**

Ipilimumab is another monoclonal antibody.

Ipilimumab works by attaching itself to normal T-cells. T-cells are part of the immune system. They fight infection and disease. T-cells can normally recognise and destroy cancer cells. Sometimes a protein on the surface of T-cells, called CTLA-4, stops this happening. Ipilimumab blocks CTLA-4, so the T-cells can destroy the cancer cell.

Ipilimumab may be given in combination with nivolumab as part of a clinical trial. It is given as a drip over about 90 minutes (1½ hours).

Your cancer doctor or specialist nurse will talk to you about the treatment in more detail if it is appropriate for you.

## **Other treatments**

In the past, the immunotherapy drugs interferon alpha and aldesleukin were commonly used to treat advanced kidney cancer. They are rarely used now, but very occasionally your doctor may recommend them. Your cancer doctor or specialist nurse can give you more information.

# Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells. Kidney cancer does not respond to radiotherapy very well. But it can be effective when used to relieve symptoms, such as bleeding. It may also be used if the kidney cancer has spread to other parts of the body, such as the brain or the bones. This is called palliative radiotherapy.

We have more information about secondary brain cancer on our website You may also find our booklet **Understanding secondary cancer in the bone** helpful (see page 104).

The treatment is given in the hospital radiotherapy department. You usually have it as an outpatient. Radiotherapy is often given as sessions called fractions. If radiotherapy is given to relieve symptoms, it is usually given for a few minutes a day for a few days. Sometimes only one fraction is needed. Your doctor will discuss the treatment plan with you.

## Side effects of radiotherapy

Radiotherapy can cause tiredness. Other side effects depend on the part of the body being treated. When radiotherapy is given to relieve symptoms, the side effects are usually mild. The doctor who plans your radiotherapy (clinical oncologist) or a specialist nurse will tell you what to expect. Usually side effects go away slowly when your course of treatment has finished. You should let your doctor know if they continue.

You may find our booklet and audiobook **Coping with fatigue** helpful (see page 104).

## Research – clinical trials

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

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

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

### Taking part in a trial

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

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

If you decide not to take part in a trial, your decision will be respected and you do not 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 are treated by the hospital staff, and you will be offered the standard treatment for your situation.

## 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.

**'The doctors, nurses and surgeon were all brilliant. But the recovery was harder than I thought it would be.'**

**Eileen**



# AFTER YOUR TREATMENT

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Well-being and recovery 79

## Follow-up

After your treatment has finished, you will have regular check-ups with your cancer doctor, urologist or nurse. They will tell you how often and for how long you will need to have these. It will depend on the type of treatment you had and the risk of the cancer coming back.

Some people will have regular tests to check for any signs of the cancer coming back. If cancer comes back in the kidney but nowhere else, it may be possible to have further surgery to remove it.

You can talk to your cancer doctor or specialist nurse about any problems or worries you have at these check-ups. But if you notice any new symptoms or have any problems between appointments, contact your doctor or nurse for advice.

Many people find they get anxious before their appointments. You may worry about the cancer coming back. This is natural. It can help to get support from family, friends or your specialist nurse. Or you can speak to our cancer support specialists on **0808 808 00 00**. Some other organisations also offer support to people affected by kidney cancer (see pages 109 to 115).

You may find our booklet **Worrying about cancer coming back** helpful (see page 104).

# Well-being and recovery

After treatment, you may just want to get back to everyday life. But you may still be coping with the side effects of treatment, adjusting to physical changes or dealing with some difficult emotions (see pages 86 to 93). Recovery takes time, so do not rush it and try to be kind to yourself.

Some people choose to make lifestyle changes to improve their health and well-being. Even if you had a healthy lifestyle before cancer, you may be more focused on making the most of your health.

If you have health problems, such as kidney disease, it is important to check with your doctor before making any changes to your lifestyle or diet.

If you have had part or all of a kidney removed, it is a good idea to look after your remaining kidney or kidneys. Reducing your risk of high blood pressure, heart problems and diabetes will help protect your kidney.

'It may help to talk with your GP about counselling. It doesn't change what's happened, but can help with the anxious feelings.'

**Christine**

## Stop smoking

If you smoke, choosing to stop is the healthiest decision you can make. Smoking is a major risk factor for smoking-related cancers, including kidney cancer. It also increases the risk of high blood pressure and heart disease. If you want to stop, your GP can give you advice. We have more information in our booklet **Giving up smoking** (see page 104).

## Eat healthily

Eating a healthy, balanced diet will give you more energy and help you recover. Try to eat plenty of fresh fruit and vegetables (5 portions a day), and less red meat. Try to limit the amount of salt you eat. This is because salt can raise blood pressure and make the kidney work harder. Follow any advice you have been given by a dietitian. We have more information about diet and cancer (see page 104).

## Drink plenty of water

Drink at least 2 litres (3½ pints) of non-alcoholic fluids a day. This will help protect your kidney. Plain water is best. Avoid bottled waters that are high in salts, such as sodium or potassium, as they make the kidney work harder.

## Stick to sensible drinking guidelines

These recommend that both men and women should not regularly drink more than 14 units of alcohol in a week. It is a good idea to have a few alcohol-free days each week. There is more information about alcohol and drinking guidelines at **[drinkaware.co.uk](http://drinkaware.co.uk)**

## Keep to a healthy weight

Keeping to a healthy weight reduces the risk of cancer, heart and kidney problems and illnesses such as diabetes. Your GP can tell you what your healthy weight is.

If you need to lose weight, ask your GP for advice. Here are some tips to help you:

- Reduce your portion size.
- Eat a balanced diet with lots of fruit and vegetables.
- Eat less fat and sugar.
- Be more physically active.

If you are following a weight-loss diet, avoid high-protein diets. These can stress the kidney. Make sure you drink plenty of fluids.

If you have lost weight during treatment, your GP or a dietitian can give you advice about gaining weight. You may find our booklets **Healthy eating and cancer**, **Managing weight gain after cancer treatment** and **The building-up diet** helpful (see page 104).

'I get out of breath some days. I think the key is to listen to your body. I'm unable to run, bike or swim any great distance now, but I'm building up slowly. Everyone is different.'

Lee

## Be physically active

Being physically active can help you manage your weight and reduce stress and tiredness. It also reduces the risk of other health conditions.

It is important to avoid injury to your kidney. You should usually avoid contact sports, such as rugby and football, and extreme sports such as skydiving.

You may find our booklet **Physical activity and cancer treatment** helpful (see page 104).

## Reduce stress

There are ways to feel less stressed. Being physically active,

'In recent years, I took up ballroom dancing with my wife, and that has been something that I really enjoyed. You can't think of anything else. It's just about your feet. It was a good day when I could do that again.'

**Peter**

eating well and getting enough sleep can help reduce stress. You could also try to make time to do things that you enjoy or

that make you laugh. Some people find it relaxing to meditate or to start a new hobby. You may find it helpful to write a journal or online blog.

## Medicines and supplements

Some painkillers, such as aspirin and ibuprofen, can damage the kidney. Ask your doctor for advice before taking over-the-counter medicines or buying vitamin or mineral supplements.

## Get your blood pressure checked regularly

High blood pressure does not always cause any symptoms. But it can be bad for the kidneys. It is important to have your blood pressure checked regularly. If it is raised, your doctor can prescribe tablets to control it.

## Urine infections

Urine infections can usually be easily treated. But if they are ignored, they can cause problems with the kidneys. If you have symptoms of a urine infection, it is important to see your GP. Symptoms include:

- smelly or cloudy urine (pee)
- pain or burning when passing urine (peeing)
- feeling you have to pass urine (pee) urgently.



# 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.

'I definitely experienced a lot of anger. The "why me" feeling was a common one. You want to know how this could happen and get answers to questions. Sometimes they don't get answered.'

**Peter**

## 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.

'My Macmillan nurse just helped me offload whenever I needed to talk. I felt better as soon as I had spoken to her. If I felt low or like I needed help, I would speak to her and afterward it lifted me tremendously.'

**Richard**

## If you need more help

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

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



# 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](https://www.macmillan.org.uk/learnzone) to find out more.

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at [macmillan.org.uk/carers](https://www.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.

'My kids are 26 and 23, and I told them about things on the phone. It was a hard thing to do and a surreal conversation. But they were okay really. They just wanted to know what the plan was and what we were dealing with.'

**Peter**

## 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.

There's also a video on our website that may help.  
Visit **macmillan.org.uk/talkingtochildren**



# WORK AND FINANCIAL SUPPORT

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# Work

You may not know how cancer will affect your work, now or in the future.

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

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

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

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful – see page 104.

There is also lots more information at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

## Employment rights

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

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

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

Our booklet **Your rights at work when you are affected by cancer** has more information – see page 104.

'I ended up having counselling through my work insurance. It was absolutely worthwhile and had some huge benefits. It was really good to be able to talk about everything, without worrying about them knowing me.'

**Peter**

# Financial help and benefits

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

## Statutory Sick Pay

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

## Benefits

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

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

## Employment and Support Allowance (ESA)

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

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

## Personal Independence Payment

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

## Attendance Allowance

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

## Special rules

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

## Help for carers

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

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

## Macmillan Grants

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

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

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

## Insurance

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

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

We have more information in our booklets **Insurance** and **Travel and cancer** – see page 104.

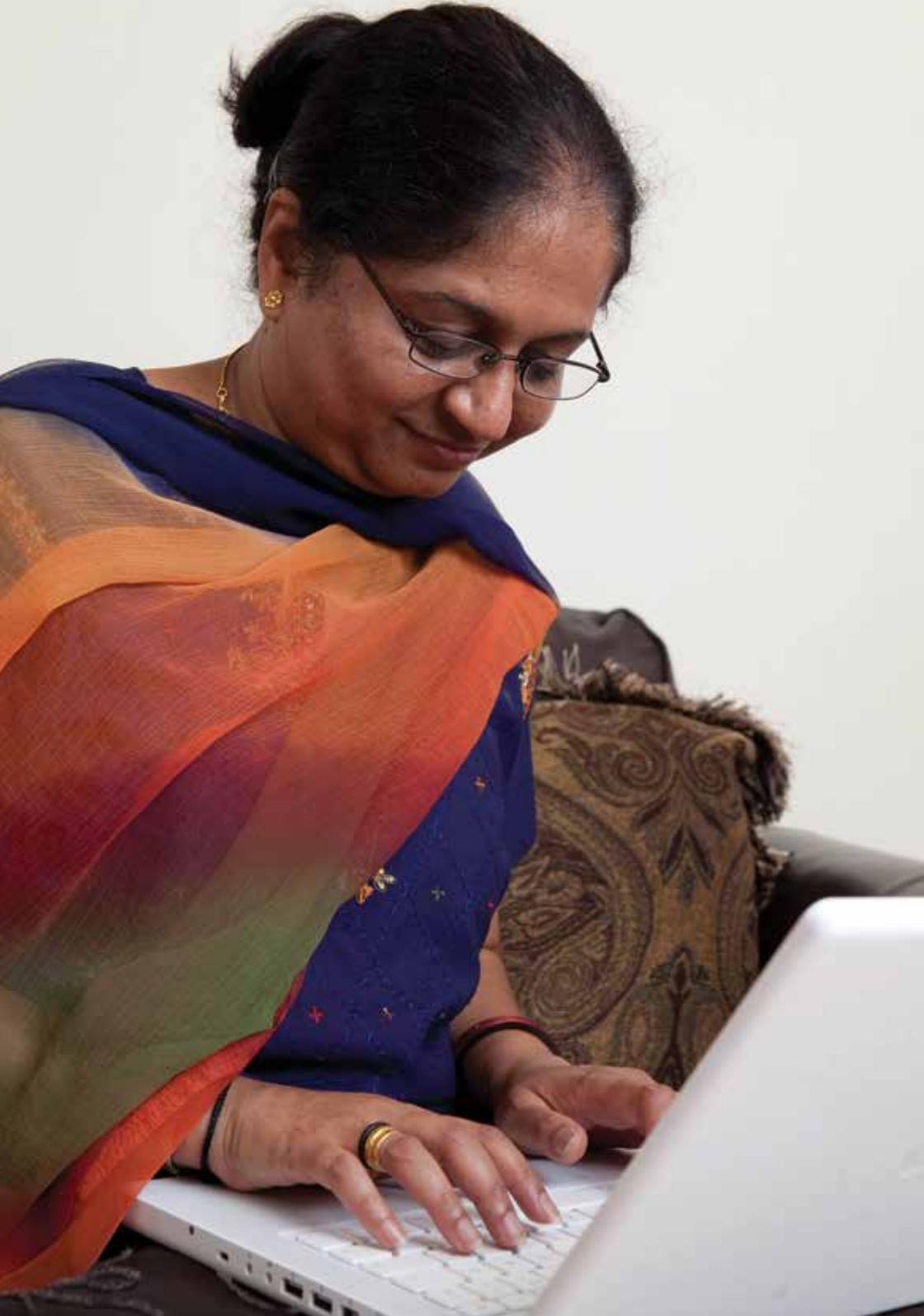
Our Online Community forum **Travel insurance** may also be helpful. Visit [macmillan.org.uk/travelinsurancegroup](https://www.macmillan.org.uk/travelinsurancegroup)

## More information

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

You can also get information about benefits and other types of financial help from Citizens Advice – see page 113 for contact details.

Our booklet **Help with the cost of cancer** has lots more information – see page 104.



# FURTHER INFORMATION

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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.

## Online information

All of our information is also available at **macmillan.org.uk/information-and-support**

There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

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

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

Find out more at **macmillan.org.uk/otherformats**

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

## Help us improve our information

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

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

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



# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

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

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://www.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](https://www.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](https://www.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](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

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

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

Mal

## Help with money worries

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

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit **[macmillan.org.uk/financialsupport](https://www.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](https://www.macmillan.org.uk/work)**

### My Organiser app

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

# Other useful organisations

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

## Kidney cancer support organisations

### Kidney Cancer UK

**Careline** 0800 002 9002

(Mon, Tue, Thu and Fri,  
10am to 4pm,  
Wed, 10am to 6pm,  
Sat to Sun, 4pm to 6pm)

**[www.kcuk.org.uk](http://www.kcuk.org.uk)**

Provides information, support and counselling for kidney cancer patients and their carers.

### Kidney Cancer Support Network

**Tel** 0120 989 0326

**Email** [team@kcsn.org.uk](mailto:team@kcsn.org.uk)

**[www.kcsn.org.uk](http://www.kcsn.org.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

**Tel** 0208 961 4151

**[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)**

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

### Cancer Focus Northern Ireland

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

**Email**

[nurseline@cancerfocusni.org](mailto:nurseline@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

### **Cancer Research UK**

**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

**www.cancerresearchuk.org**

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### **Cancer Support Scotland**

**Tel** 0800 652 4531

(Mon to Fri, 9am to 5pm)

**Email** [info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

**www.cancersupportscotland.org**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### **Maggie's Centres**

**Tel** 0300 123 1801

**Email**

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**www.maggiescentres.org**

Has a network of centres in various locations throughout the UK.

Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

### **Penny Brohn UK**

**Helpline** 0303 300 0118

(Mon to Fri, 9.30am to 5pm)

**Email**

[helpline@pennybrohn.org.uk](mailto:helpline@pennybrohn.org.uk)

**www.pennybrohn.org.uk**

Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

### **Tenovus**

**Helpline** 0808 808 1010

(Daily, 8am to 8pm)

**Email**

[info@tenovuscancercare.org.uk](mailto:info@tenovuscancercare.org.uk)

**www.tenovuscancercare.org.uk**

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

## General health information

### Health and Social Care in Northern Ireland

**[www.hscni.net](http://www.hscni.net)**

Provides information about health and social care services in Northern Ireland.

### Healthtalk

**Email** [info@healthtalk.org](mailto:info@healthtalk.org)

**[www.healthtalk.org](http://www.healthtalk.org)**

Has information about cancer, and videos and audio clips of people's experiences.

Also provides advice on topics such as making decisions about health and treatment.

### NHS.UK

**[www.nhs.uk](http://www.nhs.uk)**

The UK's biggest health information website.

Has service information for England.

### NHS Direct Wales

**[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

NHS health information site for Wales.

### NHS Inform

**Helpline** 0800 224 488

(Mon to Fri, 8am to 10pm,  
Sat and Sun, 9am to 5pm)

**[www.nhsinform.scot](http://www.nhsinform.scot)**

NHS health information site for Scotland.

### Patient UK

**[www.patient.info](http://www.patient.info)**

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics.

Also reviews and links to many health- and illness-related websites.

## Cancer registries

### The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

#### National Cancer Registration and Analysis Service

**Tel** 0207 654 8000

**Email** [enquiries@phe.gov.uk](mailto:enquiries@phe.gov.uk)

**www.ncras.nhs.uk**

**Tel** (Ireland) 021 4318 014

**www.ncri.ie** (Ireland)

#### Scottish Cancer Registry

**Tel** 0131 275 7050

**Email** [nss.csd@nhs.net](mailto:nss.csd@nhs.net)

**www.isdscotland.org/**

**Health-Topics/Cancer/**

**Scottish-Cancer-Registry**

#### Welsh Cancer Intelligence and Surveillance Unit (WCISU)

**Tel** 0292 037 3500

**Email** [general.enquiries@wales.nhs.uk](mailto:general.enquiries@wales.nhs.uk)

**www.wcisu.wales.nhs.uk**

#### Northern Ireland

#### Cancer Registry

**Tel** 0289 097 6028

**Email** [nicr@qub.ac.uk](mailto:nicr@qub.ac.uk)

**www.qub.ac.uk/nicr**

## Counselling

### UK Council for

### Psychotherapy (UKCP)

**Tel** 0207 014 9955

**Email** [info@ukcp.org.uk](mailto:info@ukcp.org.uk)

**www.psychotherapy.org.uk**

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## Emotional and mental health support

### Mind

**Helpline** 0300 123 3393

(Mon to Fri, 9am to 6pm)

**Text** 86463

**Email** [info@mind.org.uk](mailto:info@mind.org.uk)

**www.mind.org.uk**

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

## Financial or legal advice and information

### Benefit Enquiry Line Northern Ireland

**Helpline** 0800 220 674

(Mon, Tue, Wed and Fri, 9am to 5pm,

Thu, 10am to 5pm)

**Textphone** 0289 031 1092

**[www.nidirect.gov.uk/money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### Citizens Advice

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

#### England

**Helpline** 0344 411 1444

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

#### Scotland

**Helpline** 0808 800 9060

**[www.citizensadvice.org.uk/scotland](http://www.citizensadvice.org.uk/scotland)**

#### Wales

**Helpline** 0344 477 2020

**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

#### Northern Ireland

**Helpline** 0289 023 1120

**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

### Department for Work and Pensions (DWP) Personal Independence Payment (PIP) Helpline

0345 850 3322

(Mon to Fri, 8am to 6pm)

**Textphone** 0345 601 6677

### Carer's Allowance Unit

**Tel** 0800 731 0297

**Textphone** 0800 731 0317

(Mon to Thu, 8.30am to 5pm,

Fri, 8.30am to 4.30pm)

**[www.gov.uk/browse/benefits](http://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](http://www.gov.uk)**

Has information about social security benefits and public services in England, Scotland and Wales.

## NiDirect

**www.nidirect.gov.uk**

Has information about benefits and public services in Northern Ireland.

## Unbiased.co.uk

**Helpline** 0800 023 6868

**Email** [contact@unbiased.co.uk](mailto:contact@unbiased.co.uk)

**www.unbiased.co.uk**

Search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

## Equipment and advice on living with a disability

### Disability Rights UK

**Tel** 0330 995 0400

**Email**

[enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

**www.disabilityrightsuk.org**

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

## Scope

**Helpline** 0808 800 3333

(Mon to Fri, 9am to 5pm)

**Email** [helpline@scope.org.uk](mailto:helpline@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.

## LGBT-specific support

### LGBT Foundation

**Tel** 0345 330 3030

(Mon to Fri, 10am to 10pm, and Sat 10am to 6pm)

**Email** [helpline@lgbt.foundation](mailto:helpline@lgbt.foundation)

**www.lgbt.foundation**

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

## Support for carers

### **Carers Trust**

**Tel** 0300 772 9600

(Mon to Fri, 9am to 5pm)

**Email** [info@carers.org](mailto:info@carers.org)

**[www.carers.org](http://www.carers.org)**

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

### **Carers UK**

**Helpline (England, Scotland and Wales)** 0808 808 7777

(Mon to Tue, 10am to 4pm)

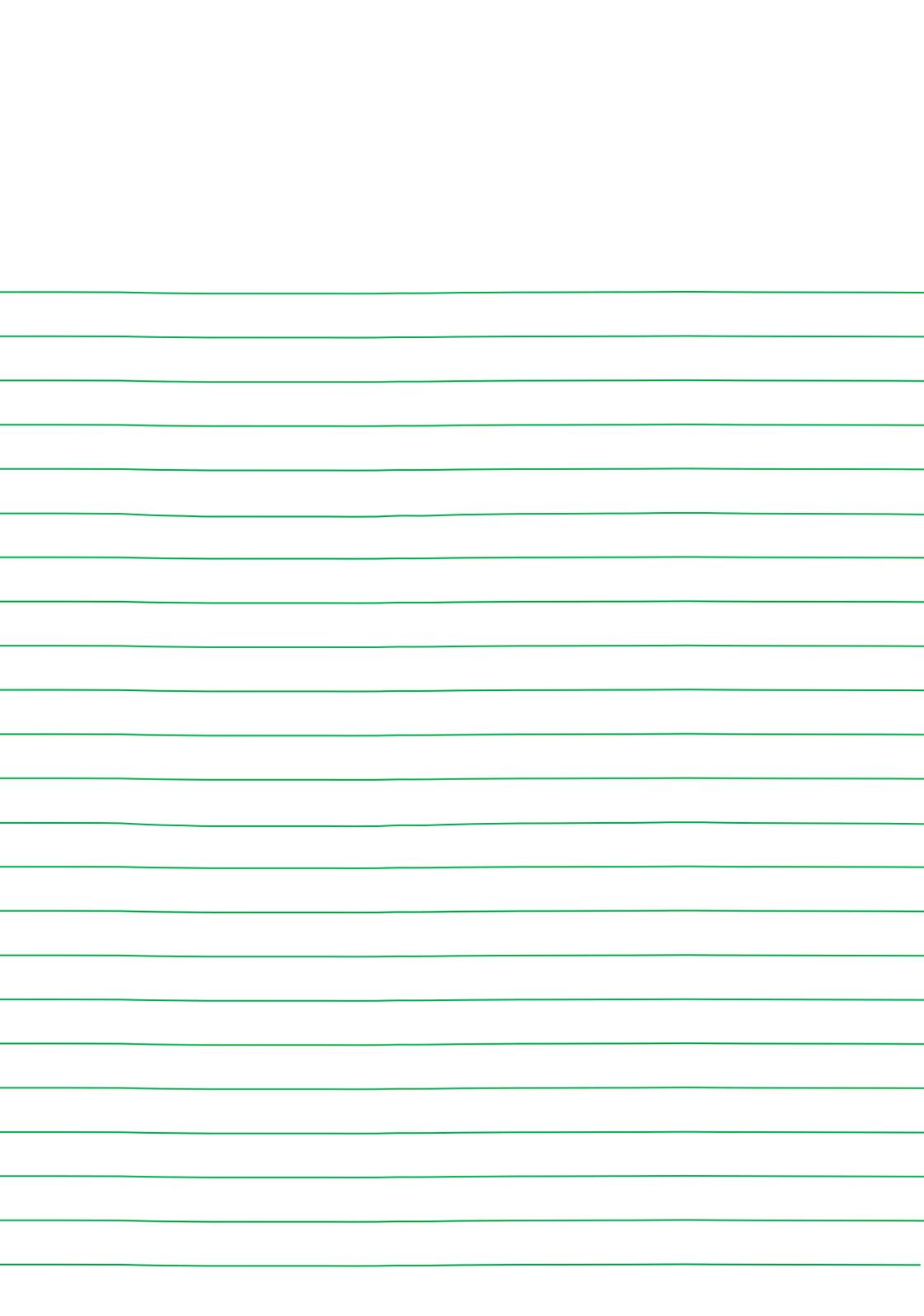
**Helpline (Northern Ireland)**

028 9043 9843

**[www.carersuk.org](http://www.carersuk.org)**

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.





## Disclaimer

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

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Lisa M Pickering, Consultant Medical Oncologist.

With thanks to: Dr Lewis Au, Clinical Research Fellow; Lesley Cooper, Renal Clinical Nurse Specialist; Dr Serena Hilman, Consultant Clinical Oncologist; Dr Peter Kirkbride, Consultant Clinical Oncologist; Mr Vinod Nargund, Consultant Urological Surgeon; and Debbie Victor, Uro-oncology Clinical Nurse Specialist.

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

We welcome feedback on our information. If you have any, please contact [\*\*cancerinformationteam@macmillan.org.uk\*\*](mailto:cancerinformationteam@macmillan.org.uk)

## Sources

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

European Association of Urology. Guidelines on renal cell carcinoma. 2015.  
National Institute for Health and Care Excellence (NICE). NICE interventional procedure guideline. Laparoscopic cryotherapy for renal cancer. August 2011.

# 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.



## **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](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other \_\_\_\_\_

Name \_\_\_\_\_

Surname \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

Postcode \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Please accept my gift of £ \_\_\_\_\_

(Please delete as appropriate)

I enclose a cheque / postal order /  
Charity Voucher made payable to  
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

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Signature \_\_\_\_\_

Date     /     / \_\_\_\_\_

## Don't let the taxman keep your money

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

- I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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



If you'd rather donate online go to [macmillan.org.uk/donate](https://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

**This booklet is about kidney cancer. It is for anyone who has been diagnosed with a type of kidney cancer called renal cell cancer. There is also information for carers, family members and friends.**

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

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**.

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

**MACMILLAN  
CANCER SUPPORT**  
**RIGHT THERE WITH YOU**

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Also operating in Northern Ireland.



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