MACMILLAN CANCER SUPPORT

Understanding kidney cancer

About this booklet

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

The booklet explains how RCC is diagnosed and treated. It has information about looking after yourself and getting support. There is also practical advice about work and financial issues. 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 kidneys. This is called upper urinary tract urothelial cancer (UTUC). It is sometimes called transitional cell carcinoma (TCC). Doctors treat it in a different way to RCC. We have separate information about this on our website at **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) has more information about Wilms' tumour – page 127.

How to use this booklet

This 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. On pages 125 to 135, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (page 136).

Quotes

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

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.

Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

Contents

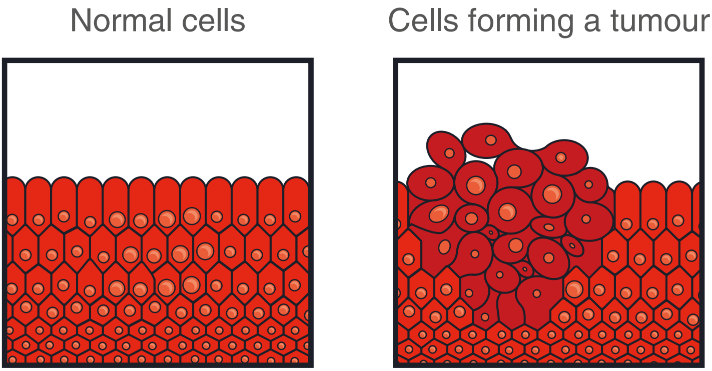
ABOUT KIDNEY CANCER

What is cancer?

Cells are tiny building blocks that make up the body’s organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system. When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

Some types of cancer start from blood cells. Abnormal cells can build up in the blood, and sometimes the bone marrow. This is where blood cells are made. These types of cancer are sometimes called blood cancers.

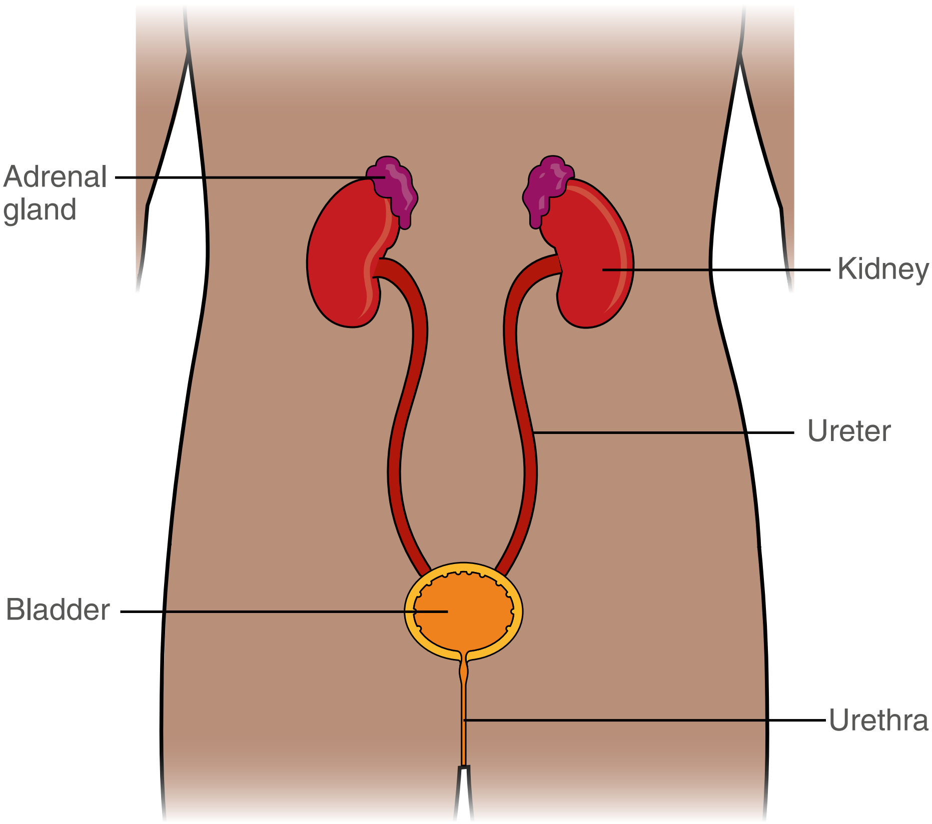
The kidneys

Most people have 2 kidneys. They sit in the tummy (abdomen), towards the back of the body. There is one on each side of the backbone (spine), just underneath the back of the ribcage.

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

On top of each kidney, there is a small gland called the adrenal gland. This makes hormones. The kidneys and adrenal glands are surrounded by a layer of fat. They are contained in a capsule of fibrous tissue.

The kidneys in the body



How the kidneys work

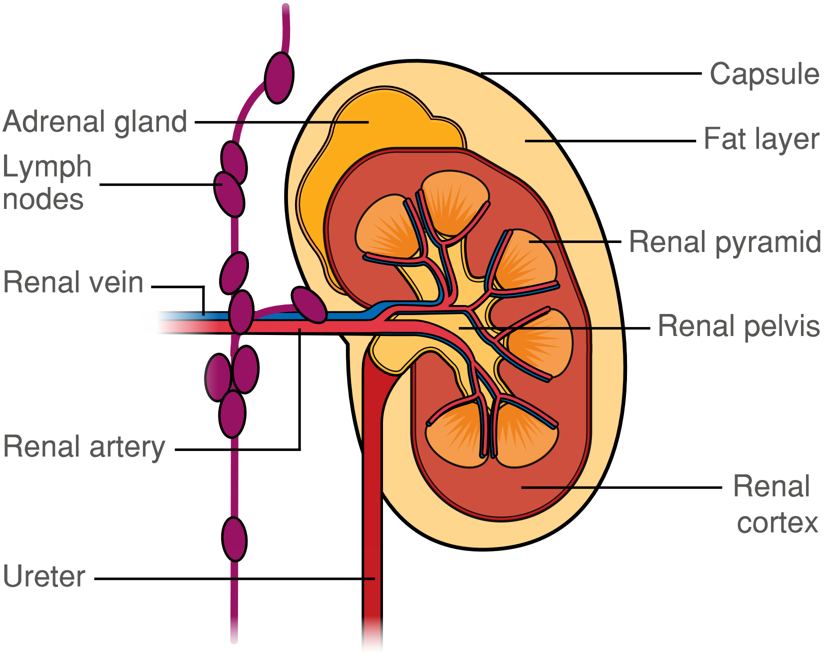
The kidneys clean the blood and keep anything the body needs. This helps control the balance of fluid, salt and minerals in the body. It also helps maintain blood pressure.

Blood goes to the kidneys through large blood vessels called the renal arteries. Inside each 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. These are made into urine. The filtered blood goes back to the rest of the body through the renal veins.

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 2 ureters – one from each kidney. The ureters connect to the bladder. The bladder is where urine is stored before it passes out of the body through another tube called the urethra.

The structure of the kidney



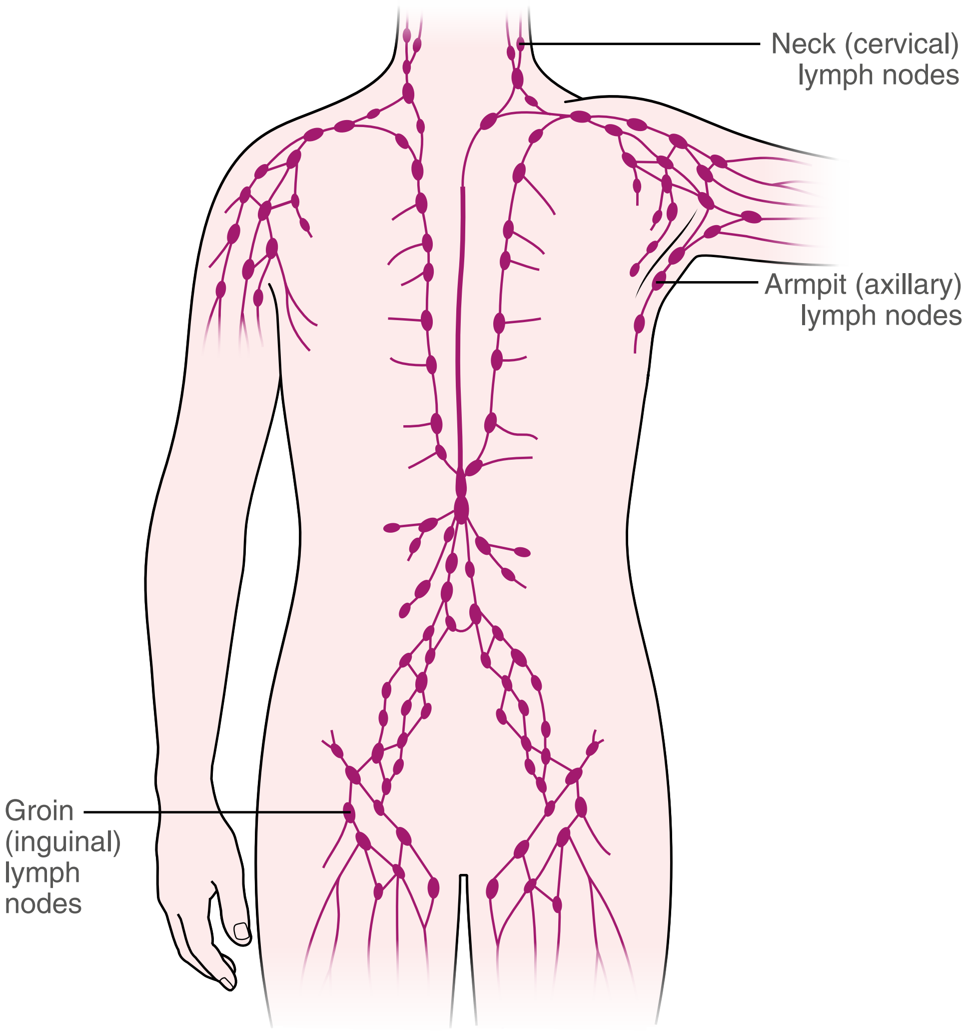
The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

Sometimes kidney cancer can spread to lymph nodes close to the affected kidney.

The lymphatic system



Kidney cancer

Each year, over 13,000 people in the UK are diagnosed with kidney cancer. Kidney cancer usually only affects one kidney. But occasionally it can affect both.

Types of kidney cancer

There are different types of kidney cancer. About 8 out of 10 kidney cancers (80%) are renal cell cancers (RCCs). They start in the cortex of the kidney (page 11).

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

- papillary RCC
- chromophobe RCC.

Kidney cancer can also start in the renal pelvis (page 11). This is usually a type of cancer called upper urinary tract urothelial cancer (UTUC) or transitional cell carcinoma. We have separate information about treating upper urinary tract urothelial cancer (UTUC) on our website – page 120.

Other very rare types of kidney cancer are renal medullary cancer (RMC) and collecting duct cancer (CDC). RMC is a fast-growing cancer linked to a blood condition called sickle cell disease. CDC has features of both RCC and UTUC. Your doctor can give you more information about RMC or CDC.

Occasionally, other cancers can be found in the kidney. These include lymphoma and sarcoma. These are not types of kidney cancer. We have separate information about these types of cancer on our website (page 120).

Risk factors and causes

The causes of kidney cancer are unknown. But there are certain things that can affect the chances of developing kidney cancer. These are called risk factors. Having a risk factor does not mean you will definitely get kidney cancer. And if you do not have any risk factors, you may still develop kidney cancer.

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

Sex

Kidney cancer is more common in men than in women.

Age

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

Smoking

Smoking increases the risk of kidney cancer. The more you smoke, the greater your risk.

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

Being overweight

Studies show that being significantly overweight (obese) increases the risk of 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 kidney cancer. The risk is greatest for people who need treatment that does the work of the kidneys (dialysis).

Waste products from the blood can sometimes cause hard stones to form in the kidneys. Men with these kidney stones have a higher risk of kidney cancer.

Diabetes

If you have type 1 diabetes, you have a higher risk of kidney cancer – particularly if you use insulin to control the diabetes rather than tablets.

Family history

Most people who get kidney cancer 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 (5%) 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
- sickle cell disease or sickle cell trait.

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

People who have had thyroid cancer have an increased risk of kidney cancer. This may be because of genetic mutations that are linked to both cancers.

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, such as lead or asbestos, may also increase risk.

Signs and symptoms

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

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

- a dull pain in your side, between the top of the tummy (upper abdomen) 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

How kidney cancer is diagnosed

Sometimes doctors see a possible kidney cancer when you are having a scan for another reason. You may not have any symptoms.

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 pee (urine). 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 may be caused by kidney cancer, they usually refer you to the hospital to see a specialist doctor. This doctor is called a urologist.

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

If your test results or symptoms suggest you may have kidney cancer, you should be seen by a specialist within 2 weeks.

Sometimes tests for kidney cancer find a kidney cyst. Kidney cysts are fluid-filled lumps. They are common and usually harmless. Your doctor may need to do further tests to check this is the case. Most cysts do not any need treatment or follow-up. But sometimes your doctor may recommend you have follow-up scans or treatment.

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 to 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

An ultrasound scan uses sound waves to create a picture of the kidneys, ureters and bladder (page 9). It is painless and only takes a few minutes.

During an ultrasound, you lie on your back and the person doing the scan spreads gel over your tummy area (abdomen). They then 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 for this.

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

CT scan

If doctors see a possible kidney cancer while doing a scan for another reason, they may request a CT scan to look at the kidneys. Your doctor or nurse may call this a triple-phase CT scan.

A CT scan takes a series of x-rays which create a three-dimensional (3D) 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 or anyone you come into contact with.

Before a CT scan, you may be given a special dye as a drink or as an injection into your arm through a small plastic tube (cannula). This allows doctors to see some areas more clearly during the scan. The dye may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is 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 done.

We have more information on our website about having a CT scan – visit **macmillan.org.uk/ct-scan**

Preparing to have a CT scan

> 'I was originally sent for a CT scan on my chest. I had what seemed like a really bad chest infection. When I got the scan results, they showed up a shadow on my kidney.'

Eileen

CT urogram

A CT urogram is a type of CT scan. It looks at the kidneys, ureters and bladder. You may have this type of scan if you have blood in your urine.

You will be given instructions on how to prepare for the scan. Before the scan, you can usually eat and drink normally. Just before the scan, you may be asked to empty your bladder.

Before a CT urogram, you will be given an injection of a dye. This helps doctors 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 are allergic to iodine. This is 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.

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 done.

Flexible cystoscopy

A flexible cystoscopy looks for changes inside the bladder. You may have this test if you have blood in the urine. You usually have this test under a local anaesthetic, so you are awake during it. Before the cystoscopy you are asked to give a sample of urine, which is checked for infection.

Before the cystoscopy, the doctor or nurse squeezes a numbing gel into the opening of the tube you pass urine from (urethra). This is the local anaesthetic. It makes the test less uncomfortable. The gel starts to work after a few minutes.

The doctor then gently passes a thin tube with a camera and light on the end (cystoscope) through the urethra and into the bladder. The test takes a few minutes and you can go home after it. You may feel some discomfort during the test, but it should not be painful.

You may have some burning or mild pain when you pee (pass urine) for a few days after the test. You may also notice some blood or blood clots in your urine. This should get better after 1 or 2 days. Your doctor will ask you to drink lots of fluids to help flush out your bladder.

Tell your doctor straight away if these symptoms do not go away or you have a high temperature. They can check to make sure you do not have an infection.

Further tests

If tests show you are likely to have kidney cancer, your doctor may want to do some further tests. These tests will give them more information about the size and position of the cancer and whether it has spread to other parts of the body. This is called staging and will help you and your doctor decide on the best treatment for you (pages 32 to 35). These may include some of the following tests.

Guided biopsy

A biopsy is when a sample of tissue is taken from the body and tested for cancer cells. Usually, the sample is collected from an abnormal area of the kidney. But if doctors think that kidney cancer has spread to a different part of the body, the sample may be taken from there. Not everyone will have a biopsy.
The doctor may decide you need a biopsy to plan the treatment most suitable for you. The doctor uses an ultrasound scan or a CT scan to guide them to the area of kidney they want to take the biopsy from.

During a biopsy, the doctor injects some local anaesthetic into the skin to numb the area around the kidney. They then guide a 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. If cancer is found, tests are used to find out more about the type (page 15) and grade of kidney cancer (pages 32 to 36).

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

CT scan

You may have a CT scan of your chest, tummy (abdomen) and pelvis (page 24). This is usually done to see whether the cancer has spread outside of the kidney to other parts of your body.

MRI scan

An MRI scan is sometimes done to see whether a kidney cancer has spread to other parts of the body, such as the bones or brain.

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.

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.

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 some of the organisations listed on pages 125 to 135 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Staging and grading

Your cancer doctor uses information from your test results to advise on the best treatment for you. This information includes the following:

- the type of kidney cancer you have (page 15)
- the stage of the cancer – this describes its size and whether it has spread
- the grade of the cancer – this gives an idea of how quickly the cancer might grow and spread.

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.

TNM staging

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

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

Tumour

T1

T1 means the cancer is only inside the kidney and is no bigger than 7cm. It is divided into:

- T1a – the cancer is 4cm or smaller
- T1b – the cancer is bigger than 4cm.

T2

T2 means the cancer is only inside the kidney and is bigger than 7cm. It is divided into:

- T2a – the cancer is between 7cm and 10cm
- T2b – the cancer is bigger than 10cm.

T3

T3 means the cancer is growing into the fat around the kidney, or into a major vein close to the kidney (the renal vein or vena cava). It is not growing outside the capsule that surrounds the kidney. T3 is divided into:

- 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

T4 means the cancer has spread through the capsule that surrounds the kidney. It may have grown into the adrenal gland.

Nodes

- N0 means there are no cancer cells in any lymph nodes near the tumour.
- N1 means there are cancer cells in 1 or more of the lymph nodes near the tumour.

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

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 – for example, the bones, lungs, liver or brain, or lymph nodes in another part of the body. If the cancer has spread, it is called secondary or metastatic kidney cancer.

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 or may not have spread to the lymph nodes.

Stage 4

The cancer has grown through the capsule that surrounds the kidney and into nearby areas. Or the cancer has 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** – a small cancer that has not spread.
- **Locally advanced** – cancer that has started to spread into surrounding tissues or nearby lymph nodes, or both.
- **Local recurrence** – cancer that has come back in the same area after treatment.
- **Secondary, advanced, widespread** or **metastatic** – cancer that has spread to other parts of the body.

Grading of kidney cancer

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 grow slowly and are 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 details of the cancer registries on page 135.

TREATING KIDNEY CANCER

Treatment overview

The treatment you will have depends on a number of factors, including:

- the position of the cancer
- the type of kidney cancer
- the stage of the cancer
- the grade of the cancer.

This information is about a type of cancer called renal cell cancer (RCC).

Your doctors will also consider how well your kidneys work, your general health and your personal preferences.

Research is being done find more effective treatments for kidney cancer. You may be invited to take part in a clinical trial for a new drug or treatment.

Early kidney cancer

If the cancer has not spread outside the kidney (stage 1 or 2), it is usually treated with surgery. 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 often do this using keyhole surgery. Surgery may be the only treatment you need.

Sometimes you may have tumour ablation treatment for early kidney cancer. This is when very high or low temperatures are used to destroy cancer cells (pages 63 to 69). In some situations, you may have this instead of surgery.

Some kidney cancers grow slowly and are very unlikely to spread outside the kidney. Some people who have small kidney cancers (usually less than 4cm) 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 (pages 74 to 75).

Locally advanced kidney cancer

Surgery is often the main treatment if the cancer is bigger or has spread to nearby lymph nodes or veins, but not to other parts of the body. You may also have immunotherapy drugs to try to reduce the risk of the cancer coming back after surgery. You may have these as part of a clinical trial.

Advanced (metastatic or secondary) kidney cancer

Targeted therapy and immunotherapy drugs are the main treatments for advanced kidney cancer. You have these treatments to try to control the cancer. They may 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 surgery is possible, you usually have it with other treatments, such as targeted therapy.

If you have a secondary cancer in only one area of the body, for example the lung, you may have surgery to that area. But this is not common. You may also have other treatments, such as radiotherapy. Occasionally, you may have surgery to manage the symptoms of advanced cancer. For example, you may have it to help prevent problems caused by kidney cancer that has spread to the bone. Some advanced kidney cancers grow very slowly. If the cancer is growing slowly and not causing symptoms, your cancer doctor may suggest monitoring the cancer with scans for a while before starting treatment.

Sometimes you have radiotherapy to:

- control kidney cancer that cannot be removed with surgery
- treat symptoms such as bleeding
- treat kidney cancer that has spread to other parts of the body.

We have more information about radiotherapy on pages 81 to 83.

How your treatment is planned

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT). The MDT will include the following professionals:

- **a urologist** – a surgeon who treats problems of the urinary system and specialises in treating kidney cancer
- **an oncologist** – a doctor who treats people who have cancer
- **a urology clinical nurse specialist (CNS)** – a nurse who gives information about kidney cancer, and support during treatment
- **a radiologist** – a doctor who looks at scans and x-rays to diagnose problems and performs tests and procedures
- **a pathologist** – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

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

Treatment decisions

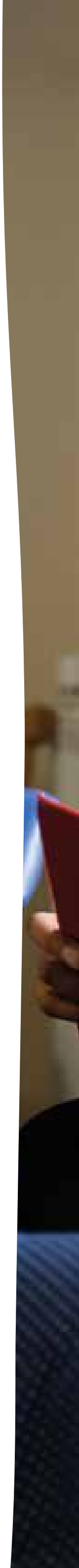
Your cancer doctor and specialist nurse will talk to you about your treatment options. They will know what the most effective treatments are. But you know your lifestyle and preferences. They will explain the options available, and they can help you if you need to make decisions about treatment.

Research into kidney cancer is happening all the time. Your cancer doctor 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. 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 can also be harder to understand things 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 permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (page 43).

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment.

Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this.

You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit **macmillan.org.uk/second-opinion**

Surgery

Surgery may be the only treatment you need. The type of surgery (operation) you have will depend on the stage of the cancer (pages 32 to 35) and 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 operation is called a partial nephrectomy or nephron-sparing surgery. It is the most common operation for kidney cancers smaller than 4cm. But you may have it if you have a larger kidney cancer. Your doctor will explain if it is suitable for you.

During the operation, the surgeon removes the part of the kidney with the cancer. The aim is to remove the cancer but to leave as much normal tissue as possible. This is so the kidney can continue to work.

You may have this operation if it is important to try to keep the affected kidney. This may be because your other kidney does not work well, or you have kidney disease or other conditions that might affect how well your kidneys work in the future. If you have an inherited type of kidney cancer, you may be offered this operation. This is because there is a risk you may develop a cancer in the other kidney.

You are likely to be referred to a specialist hospital for this type of surgery. This may mean you have to travel for treatment.

Removing the whole kidney

This operation is called a radical nephrectomy. You may have this operation if the cancer is bigger. Or you may have it if the cancer is in the middle of the kidney and a partial nephrectomy is not suitable.

During the operation, the surgeon removes the whole kidney and some surrounding tissue. They also remove lymph nodes close to the kidney to check them for cancer cells.

You can usually live a normal life with 1 kidney. It will be able to do the work of both kidneys. The surgeon can talk to you about this before you make a decision about having surgery.

Removing a kidney is a big operation and is not suitable for everyone. Your doctors may need to do tests to check you are well 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 surgery. 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

Your doctors may talk to you about an operation to remove the kidney even if the cancer has spread. It will not cure the cancer, but in some people, it can mean that they are likely to live longer. Your treatment plan will usually include other treatments such as immunotherapy (pages 79 to 80) and targeted therapy (pages 76 to 78).

You may 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.

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

Types of 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. For kidney cancer surgery, you usually have a general anaesthetic.

Kidney cancer surgery is commonly done as keyhole surgery, but open surgery is sometimes needed.

Keyhole (laparoscopic) surgery

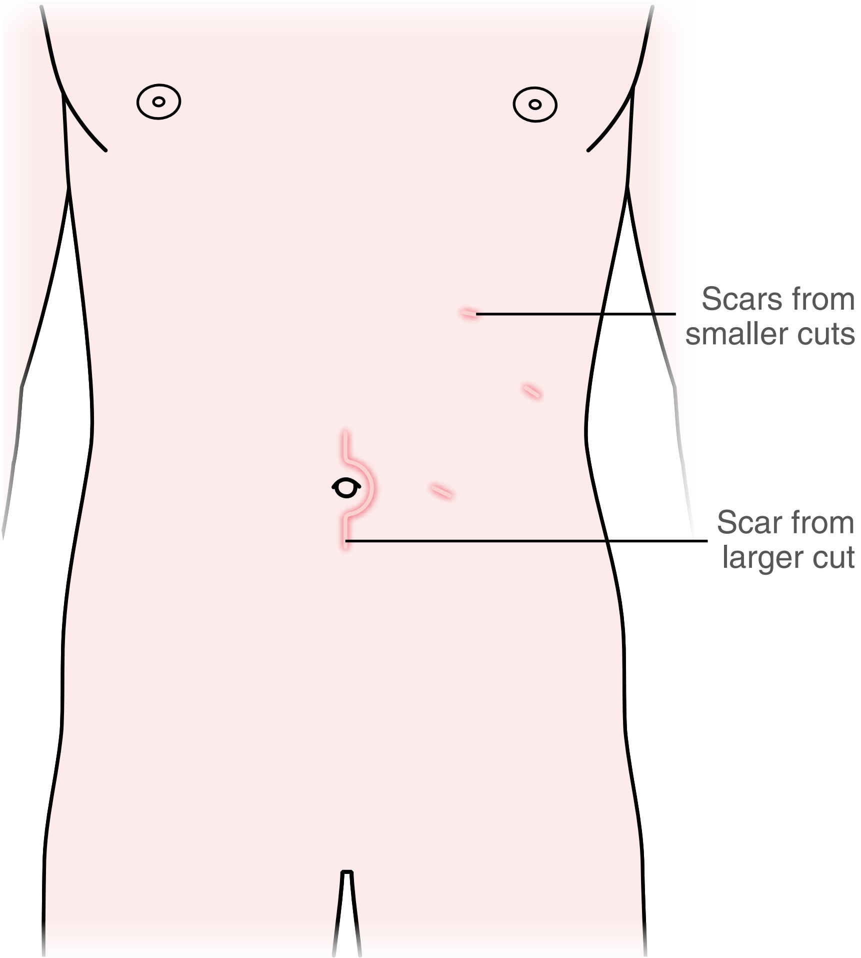
During keyhole surgery, the surgeon uses a laparoscope to see and work inside the tummy (abdomen). A laparoscope is a thin tube with a light and camera on the end. It sends video images to a monitor.

The surgeon starts by making 3 or 4 small cuts in the tummy. They then put the laparoscope through one of the small cuts in the skin. Your tummy will be inflated with gas to help the surgeon operate more easily.

During the operation, the surgeon puts the kidney they want to remove into a bag inside your body. At the end of the operation, they either make one of the cuts bigger, or they make an extra cut. This is so they can remove the bag with the kidney inside.

The position of the cuts depends on who is having the surgery and how the surgeon does the operation. Your surgeon can talk to you about what to expect. Recovery from keyhole surgery is usually quicker than from open surgery. This is because the wounds are smaller.

Keyhole kidney surgery scars



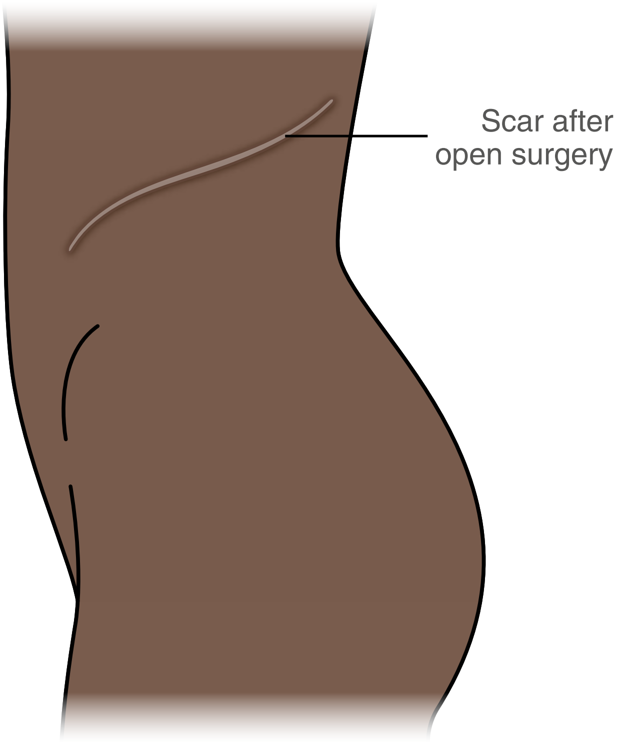
Robot-assisted surgery

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. The robot makes it possible for the surgeon to move in a very precise way to do complicated keyhole surgery.

Open surgery

During open surgery, the surgeon makes one large cut (incision) just under the bottom rib or between the 2 bottom ribs. This cut can be up to 30cm long. After the operation, the surgeon stitches or staples the wound closed.

Open surgery scar



Surgery to remove a secondary cancer

Rarely, you may have an operation to remove a secondary cancer in another part of the body. This is a very specialised operation. It is usually only possible if the cancer has spread to a limited area – usually just to one place in the body, such as the lung or the brain. 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. Or it may help reduce any symptoms it might be causing. Occasionally, it may be used to try to cure the cancer.

Before your operation

Before your operation, you will visit a pre-assessment clinic. You will be asked about your medical conditions and any medication you take.

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 about 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 (anaesthetist), either at a clinic or when you go into hospital for your operation.

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.

Some people may need help when they go home after surgery. For example, you may need support if you live alone or care for someone else. If you think you may need help when you go home, tell your doctors and nurses as soon as possible. They can help make arrangements 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 supplements to drink.

You will usually go into hospital (be admitted) 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.


AYMES

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. This is called an intravenous infusion. It gives you fluids until you are able to eat and drink again. It may also give you painkillers and other medications. When you are eating and drinking normally again, it is taken out.

You may have a tube (catheter) put in during the operation to drain urine (pee) from the bladder. You may only have it for 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 sick for the first few 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. If you had keyhole surgery (pages 52 to 54), the gas in your tummy can make you feel uncomfortable for a few days. The feeling goes away as your body absorbs the gas.

Pain and discomfort can be controlled with painkillers. For the first 1 to 2 days after your operation, you will usually have one or more of the following:

- A pump attached to a small tube 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.
- Tablets or syrup.

By the time 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 feel some aching and mild pain close to the scar for several weeks after surgery.

Moving around

Moving around helps you recover more quickly. It also reduces the risk of complications.

The nurses will encourage you to get up fairly soon after your operation. The hospital ward staff will help you with this. They can help you wash and go to the toilet. When 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 anticoagulant. A nurse will inject it under the skin, usually in the tummy. The injections usually continue for 28 days. A nurse will show you, or a family member 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

If you have open surgery, the surgeon will close the wound using staples or stitches (page 54). A practice nurse at your GP surgery can remove the staples 7 to 10 days after the operation. The stitches are usually dissolvable, so they do not need to be removed.

Tell your nurse or doctor straight away if your wound:

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

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. Tell them straight away if you:

- feel unwell
- have any bleeding
- notice swelling and redness in a limb (arm or leg).

You should also tell them if you have symptoms of an infection, such as a cough or a leaking wound.

You will be given a telephone number to call if you need advice when you get home.

After open surgery to the kidney (page 54), some people develop a bulge (swelling) along their scar. Doctors call this an incisional hernia. It can happen because of weakness in the muscles around the scar. Tell your doctor or nurse 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 open surgery, most people go home after 5 to 7 days.

Your body uses a lot of energy to heal. 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 such as shopping, driving, having sex, playing sport or going to work.

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.

Tumour ablation

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

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

It may be done if it is important to try to keep the affected kidney, or if you have only 1 kidney. It can also be an option if you 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 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 tumour ablation is an option for you.

There are different methods for destroying the tumour. The 2 most commonly used treatments are:

- cryotherapy – this uses liquid nitrogen to freeze the tumour (page 66)
- radiofrequency ablation (RFA) – this uses an electric current to produce high temperatures to destroy the tumour (page 67).

Other methods of tumour ablation may be used in clinical trials. These include:

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

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

Before tumour ablation, you should have a guided biopsy to collect a tissue sample (page 29). This is to give your doctor more information about the cancer. Or your doctor may decide to take a sample during the treatment.

How tumour ablation is done

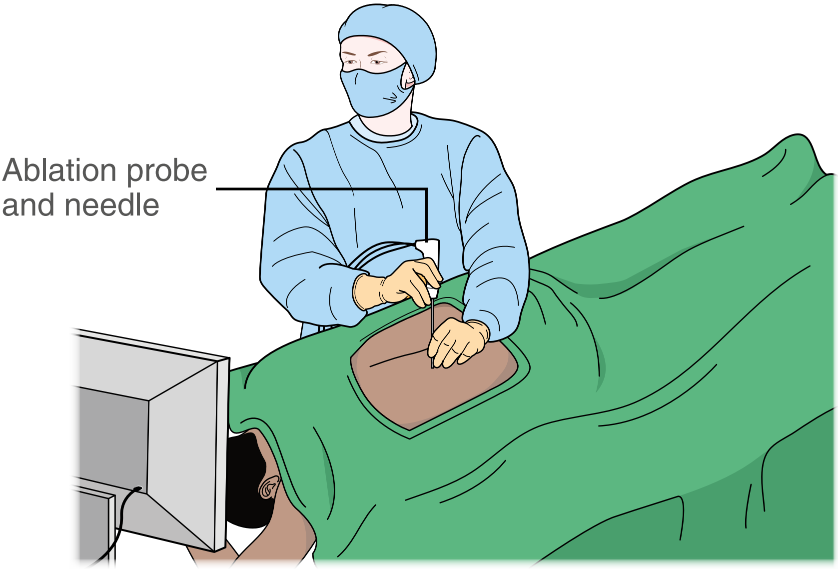
Usually, a specialist x-ray doctor (radiologist) will do tumour ablation. You will either be given a sedative to help relax you, or a general anaesthetic.

You may have a catheter put in to drain urine from your bladder. This is usually removed soon after the procedure.

The doctor uses a local anaesthetic to numb the area around the kidney. Then you have an ultrasound (page 23) or CT scan (page 24). These scans guide the doctor to the right area of the kidney. The scans also help them monitor what is happening during your treatment.

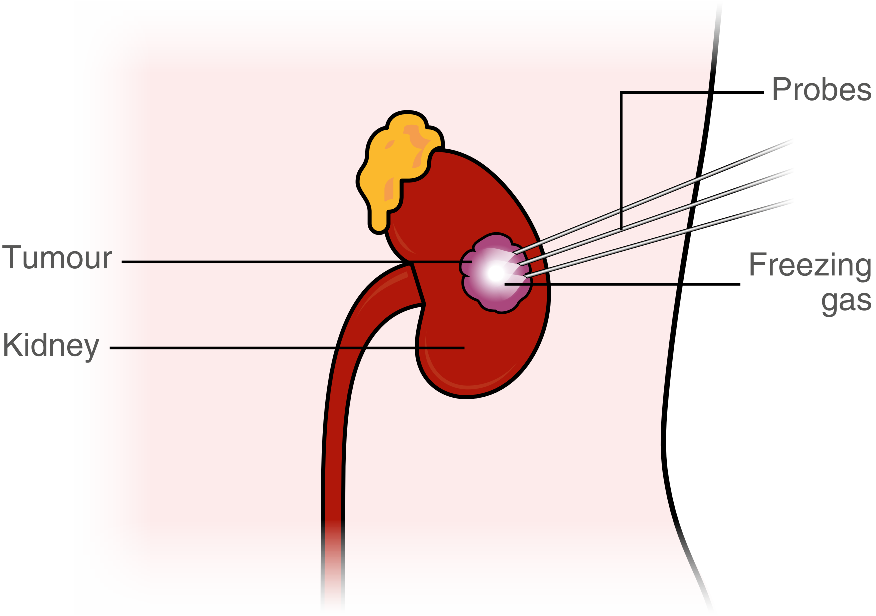
When the doctor sees the tumour on the monitor, they place 1 or more fine probes through the skin (percutaneously) into the tumour.

Having tumour ablation

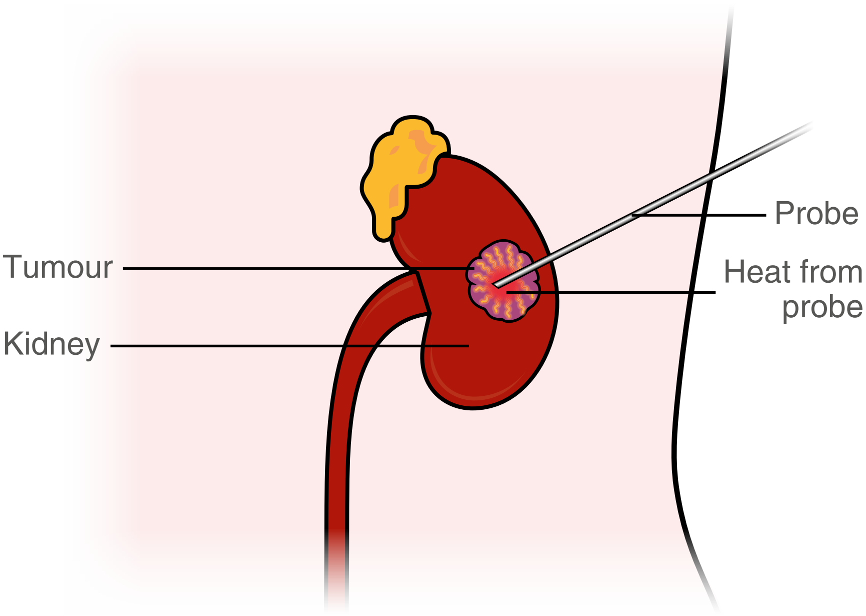


The probes freeze or heat the tumour. The extreme temperature destroys the cancer cells. The doctor will also aim to destroy a small area (about 1cm) of healthy tissue around the tumour. This is to try to make sure no cancer cells are left behind to grow back again.

Close-up of cryotherapy



Close-up of radiofrequency ablation (RFA)



Sometimes a tumour ablation is done using keyhole surgery. You have a general anaesthetic for keyhole surgery. The surgeon makes a few small cuts in your tummy (abdomen) to do the tumour ablation. They pass a laparoscope through one of the cuts to see the tumour. A laparoscope is a thin tube with a light and a camera on the end that sends video images to a monitor. The surgeon inflates your tummy with gas so that it is easier to see and work with the laparoscope.

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. If you had gas in your tummy for the laparoscope, you may feel bloated and have some discomfort in your shoulders. This improves over a few days as your body absorbs the gas.

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. This may be caused by an infection.

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

You usually need to stay in a hospital bed for 4 to 6 hours after the treatment.

Possible complications

The risk of complications after tumour ablation is low.

Possible complications include:

- 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 ureter – this can affect how urine drains from the kidney (pages 8 to 9).

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

Going home after tumour ablation

After tumour ablation, you may go home on the same day or on the day after treatment. This depends on how quickly you recover.

Your surgeon or nurse can tell you when you can start doing everyday activities again.

Before you leave hospital, you will be given an appointment for a check-up. This will be at an outpatient clinic. Your doctor or nurse may arrange for you to have a CT scan to see the result of the treatment (page 24).

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

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. Arterial embolisation cannot cure the cancer by itself. But it can help control symptoms, such as pain or bleeding.

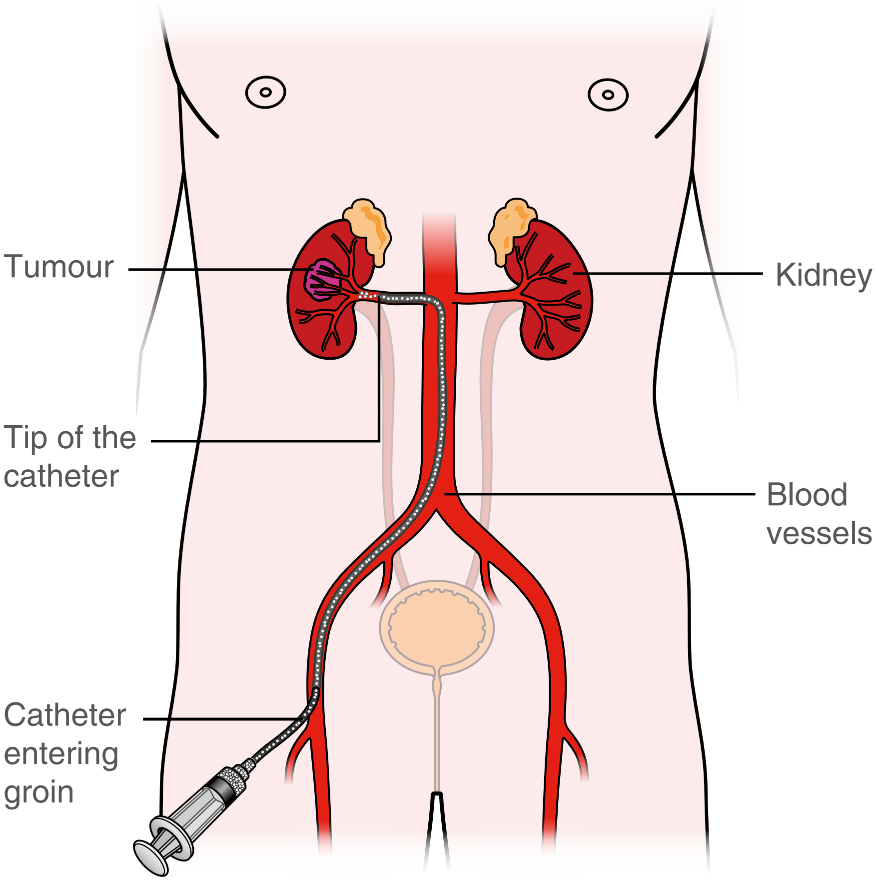
You may be offered arterial embolisation if an operation is not possible for you.

How arterial embolisation is done

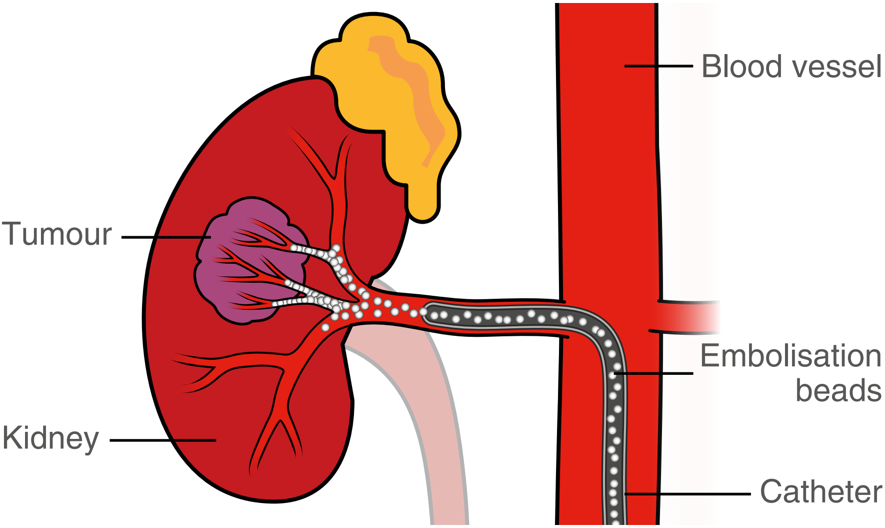
Before treatment, the nurse or doctor usually gives you a mild sedative to help you relax. They then inject some local anaesthetic into the skin at the top of the leg (the groin) to numb the area.

A doctor puts a thin, plastic tube (catheter) into a blood vessel in the groin. 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. They then inject a substance, such as tiny beads, through the catheter into the artery. This blocks the blood supply to the cancer.

Tumour embolisation



Close-up of tumour embolisation



Side effects of arterial 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.

Going home after arterial embolisation

After arterial embolisation, you may need to stay in hospital overnight, or possibly for a day or 2 longer, depending on how quickly you recover.

Your surgeon or nurse can tell you when you can start doing everyday activities again.

Before you leave hospital, you will be given an appointment for a check-up. This will be at an outpatient clinic. Your doctor or nurse may also arrange for you to have a CT scan to see the result of the treatment (page 24).

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

Monitoring

Monitoring a kidney cancer is way of delaying treatment until it is needed. It is sometimes called active surveillance.

During monitoring, you have regular ultrasound, CT or MRI scans. The scans look for signs that the cancer is growing. Sometimes you have a guided biopsy to give your doctor more information about the cancer (page 29).

Your cancer doctor or specialist nurse may talk to you about starting treatment if:

- the scans or biopsy show signs the cancer is growing
- your symptoms change.

The main advantage of monitoring is that you can avoid the risks or side effects of treatment.

Monitoring is an option for some people who have very small, slow-growing kidney cancers (under 4cm). 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.

If you have kidney cancer that has spread to other parts of the body, but you do not have symptoms, you may also have monitoring to delay starting targeted therapy or immunotherapy treatment.

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. You could talk to family or friends, keep a journal or join a support group. The Macmillan Online Community also has a kidney cancer group. Visit **community.macmillan.org.uk/cancer_types/kidney-cancer-forum**

Targeted therapy

Targeted therapies affect the way that cancer cells grow.

Targeted therapy drugs are used to treat 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. Your cancer doctor or specialist nurse will tell you if they think targeted therapy drugs are suitable for you.

Tyrosine kinase inhibitors (TKIs)

Tyrosine kinase inhibitors (TKIs) are a type of targeted therapy used to treat kidney cancer. 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.

Some drugs 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.

These are the TKIs used to treat renal cell cancer RCC (page 15):

- sunitinib (Sutent®)
- pazopanib (Votrient®
- tivozanib (Fotivda®)
- cabozantinib (Cabometyx®)
- axitinib (Inlyta®)
- lenvatinib (Kisplyx®), which is given in combination with a different type of targeted therapy called everolimus – everolimus can also be used on its own.

You take these treatments as tablets or capsules. You will usually continue taking a targeted therapy drug for as long as it is keeping the tumour under control. You will have regular CT scans to check this (page 24).

It is important to tell your doctor or nurse about any side effects, as these can usually be managed. You may need to stop treatment or have a short break if you have very difficult side effects.

All the targeted therapy drugs listed here are licensed to treat kidney cancer and can be used in the UK. These targeted therapy drugs all work in a similar way. So, if you have had a TKI before, some of the others might not be suitable for you. Most people have 1 or 2 as part of their treatment over time.

You may have TKIs on their own or with immunotherapy (pages 79 to 80). You may have targeted therapy as part of a clinical trial (pages 84 to 85).

Side effects of targeted therapies

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

- tiredness
- feeling sick (nausea)
- sore mouth
- diarrhoea
- skin rashes
- sore hands and feet
- high blood pressure
- change in hair colour
- the thyroid gland not working properly (underactive thyroid).

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 help control and manage them.

Wounds may take longer to heal when you are having treatment with targeted therapies. You may need to stop treatment before having an operation or dental treatment. Your doctor will talk to you about this.

Targeted therapies can react with some medicines and foods. Before you start treatment, tell your cancer doctor about any medicines you are taking. You should also tell your GP that you are having targeted therapy treatment. Your doctors can tell you whether there are any foods you should avoid.

We have more information about individual targeted therapy drugs, how they are given and their side effects at **macmillan.org.uk/targeted-therapy**

Immunotherapy

Immunotherapy drugs encourage the body's immune system to fight cancer cells. They are used to treat kidney cancer that has spread to other parts of the body (advanced or metastatic kidney cancer) – pages 32 to 36. Immunotherapy is not suitable for people with certain medical conditions.
Your doctor can talk to you about this.

The following immunotherapy drugs are used to treat kidney cancer (renal cell cancer). These drugs are also called checkpoint inhibitors:

- nivolumab (OPDIVO®)
- ipilimumab (Yervoy®) – given in combination with nivolumab
- pembrolizumab (Keytruda®) – given in combination with a TKI called axitinib (Inlyta®)
- avelumab (Bavencio®) – given in combination with axitinib.

Other combinations of checkpoint inhibitors and TKIs are being studied in clinical trials. These treatments may become available when the results are known.

You have checkpoint inhibitors as a drip into a vein (intravenously). Treatments may not be widely available on the NHS for all types of kidney cancer. Some people have immunotherapy as part of a clinical trial (pages 84 to 85). If a drug is not available, there may be different ways you can still have it. Your doctor may be able to apply for funding to get it if it is appropriate for you.

Side effects of immunotherapy

Checkpoint inhibitors can make the immune system too active. This can cause inflammation in parts of the body. The most common parts it can affect are the:

- skin – causing a rash
- thyroid gland – causing it to become overactive or underactive
- bowels – causing diarrhoea
- joints – causing pain and swelling.

More rarely, these drugs cause problems in other places such as the liver, lung, heart, nerves, brain, or other organs. This type of side effect may start weeks, months, or sometimes more than a year, after you finish treatment.

Some people have very few side effects. But the side effects of checkpoint inhibitors can be serious. If you have any symptoms or side effects that start during treatment or after treatment finishes, contact your doctor or hospital straight away.

We have information about individual checkpoint inhibitor drugs and their side effects at **macmillan.org.uk/immunotherapy**

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells.

You may have radiotherapy to:

- control kidney cancer that cannot be removed with surgery
- treat the symptoms of kidney cancer – such as bleeding
- treat kidney cancer cells that have spread to other parts of the body – such as the lung, brain or bones.

Sometimes you have radiotherapy as part of a clinical trial (pages 84 to 85).

When you have radiotherapy to control a cancer, treat symptoms or treat cancer that has spread to other parts of the body, it is called palliative radiotherapy.

Palliative radiotherapy may be given to control the cancer for longer when it is not possible to cure it.

Types of radiotherapy

Radiotherapy for kidney cancer is given using a radiotherapy machine outside the body. This is called external beam radiotherapy.

There are different ways of having external radiotherapy:

- Intensity-modulated radiation therapy (IMRT) and volumetric modulated arc therapy (VMAT) – these both shape the radiotherapy beams to give different doses of radiotherapy to different parts of the treatment area. This means lower doses of radiotherapy are given to the healthy tissue surrounding the tumour.
- Stereotactic ablative body radiotherapy (SABR) – this is sometimes called stereotactic body radiation therapy (SBRT). It uses many small beams of radiation to target the cancer. This makes it very precise. It means high doses of radiotherapy can be given to very small areas. This can reduce the risk of side effects.

Your clinical oncologist or radiographer can tell you more about these radiotherapy treatments and whether they are suitable for you.

Some treatments may not be available in all radiotherapy centres. If a type of radiotherapy is not available at your local hospital, your doctors may arrange for you to have it at another treatment centre.

You usually have radiotherapy as an outpatient. You usually have it as sessions called fractions. Your doctors will explain how many fractions you will have. You may only need 1 fraction.

Side effects of radiotherapy

Radiotherapy can cause tiredness. Other side effects depend on the part of the body being treated.

When you have radiotherapy to relieve symptoms, the side effects are usually mild. Your 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 tell your doctors if they continue.

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have. They will also explain the possible benefits and any possible risks of the trial.

Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have. We have more information about cancer clinical trials at **macmillan.org.uk/clinical-trials**

Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

AFTER YOUR TREATMENT

> Following surgery,
> I have been lucky.
> My 5-year CT scans and follow-ups have shown no evidence of visible disease. Kidney cancer is unpredictable. I remain vigilant and proactive about my cancer survival.

Rose

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 check-ups. This will depend on the type of treatment you had and the risk of the cancer coming back. If you have advanced cancer, it will depend on any treatment you need to help control the cancer.

Some people will have regular blood tests (page 23) and CT scans (page 24) or chest x-rays 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 cancer doctor or nurse for advice.

Many people feel anxious before their appointments. You may worry about the cancer coming back (pages 98 to 103). 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 (page 125).

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 or adjusting to physical changes. You may also be dealing with some difficult emotions. Recovery takes time, so do not rush. 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 the kidneys.

Stop smoking

If you smoke, giving up 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.

The NHS has a lot of information and support to help you give up smoking. Visit the NHS website for the country where you live (page 127).

Eat healthily

Eating a healthy, balanced diet will give you more energy and help you recover. Try to eat 5 portions of fresh fruit and vegetables each day. And try to eat less red meat. Try to limit the amount of salt you eat. This is because salt can raise blood pressure and make the kidneys work harder. Follow any advice you have been given by a dietitian.

Drink plenty of water

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

Keep to sensible-drinking guidelines

NHS guidelines suggest that you should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units you drink in a week over 3 or more days
- try to have several alcohol-free days every week.

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, one small glass (125ml) of wine, or a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at **drinkaware.co.uk**

Keep to a healthy weight

Keeping to a healthy weight reduces the risk of cancer. It also reduces the risk of 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. You may also want to try:

- reducing your portion size
- eating a balanced diet with lots of fruit and vegetables
- eating less fat and sugar
- being more physically active.

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

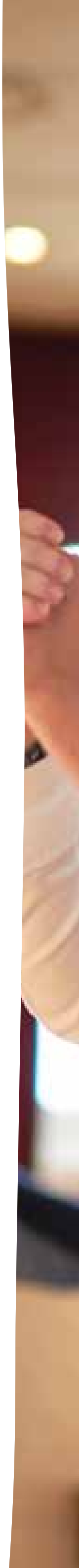
If you have lost weight during treatment, your GP or a dietitian can give you advice about gaining weight.

Be physically active

Being physically active can:

- help you manage your weight
- reduce stress and tiredness
- reduce the risk of other health conditions, such as diabetes.

It is important to avoid injury to your kidneys. You may have to avoid contact sports, such as rugby and football, and extreme sports such as skydiving.



> In recent years, I took up ballroom dancing with my wife and that has been something that I really enjoyed. It was a good thing to do while I was dealing with the diagnosis.
>
> **Peter**

Reduce stress

Being physically active, eating well and getting enough sleep can help reduce stress. 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 blog.

Medicines and supplements

Some painkillers, such as aspirin and ibuprofen, can damage the kidneys. 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 GP 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 speak to your GP.

Symptoms include:

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

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups**

You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

> **‘My Macmillan nurse 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 afterwards it lifted me tremendously.’**
>
> **Richard**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information about coping with the emotional effects of cancer in our booklet **How are you feeling? The emotional effects of cancer** (page 120).

Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is 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. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information about talking to someone with cancer in our booklet **Talking with someone who has cancer** (page 120).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (page 120).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

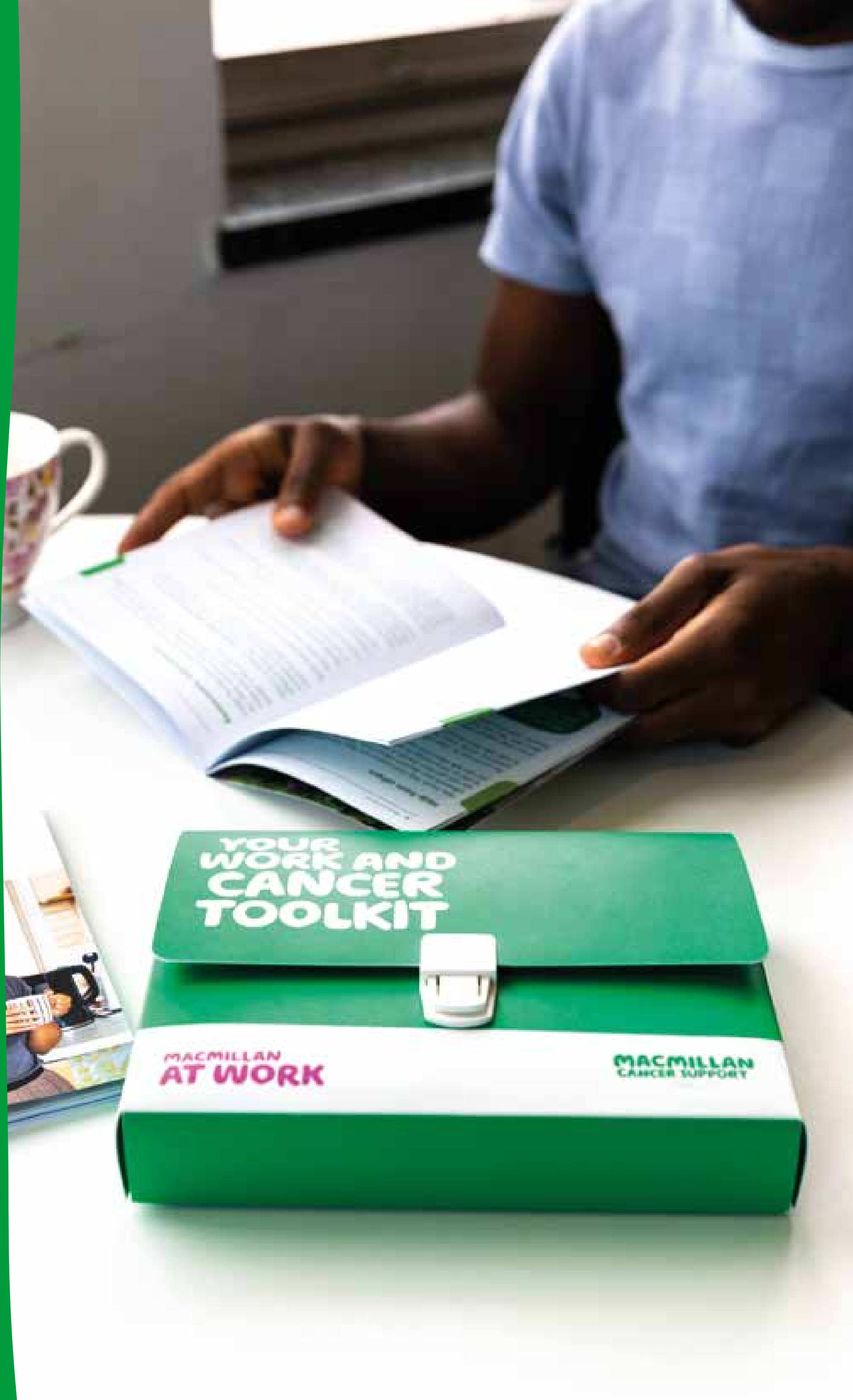
Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online.

We have more information about talking to children and teenagers when an adult has cancer in our booklet **Talking to children and teenagers when an adult has cancer** (page 120).

WORK AND FINANCIAL BENEFITS


YOUR WORK AND CANCER TOOLKIT
MACMILLAN AT WORK
MACMILLAN CANCER SUPPORT

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 or 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 have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 12 months. 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 12 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 to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to 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.

Grants

You may be able to get some financial help from other charities – for example, one-off grants. For further information, contact the Macmillan Support Line for free on **0808 808 00 00**.

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 thinking about buying insurance or making a claim, one of our money advisers can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (page 120). Our Online Community forum on **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

> **As I was taking some time to recover from my kidney operation, I was spending more time at home and keeping the heating on for longer. Though I was signed off work on sick pay, it wasn't enough to cover the higher costs of heating my home, so the grant really did make a difference.**
>
> **Linda**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced money advisers. 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 Advice NI and Citizens Advice (pages 129 to 130).

Our booklet **Help with the cost of cancer** has lots more information (page 120).

> **‘I didn’t really want to own up to the fact that I needed some help or that cancer had got me. It took me a little while to take things into my own hands and make an appointment to speak to Macmillan – but what a relief it was when I did.’**

Linda

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 soon after you are diagnosed. 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 keep 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 do 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 (page 120). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

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 (page 120).

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **orders.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring 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
- interactive PDFs
- large print
- translations.

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

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

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as ‘you’ so that everyone feels included. Where clinically necessary we use the terms ‘men’ and ‘women’ or ‘male’ and ‘female’. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are 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 support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our nurses about things like diagnosis and treatments from our nurse specialists
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support-line** to chat online and see the options and opening times.

Macmillan Information and Support 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 would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

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

Help with money worries

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

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 00 00**. Visit **macmillan.org.uk/financialsupport** for more information about benefits.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Kidney cancer support organisations

Kidney Cancer Support Network

Tel **01209 890326** (Mon to Fri, 10am to 4pm)
Email **team@kcsn.org.uk**
www.kcsn.org.uk
Helps kidney cancer patients, families and friends join together and offer information, advice and friendship to each other.

Kidney Cancer UK

Careline **0800 002 9002**
www.kcuk.org.uk
Provides information, support and counselling for kidney cancer patients and their carers.

General cancer support organisations

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)
Email **nurseline@cancerfocusni.org**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer 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.

Macmillan Cancer Voices

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

Maggie’s

Tel **0300 123 1801**
Email **enquiries@maggies.org**
www.maggies.org
Has a network of centres in many 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 3000 118** (Mon to Fri, 10am to 2pm)
Email **info@pennybrohn.org.uk**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
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.

The Children's Cancer and Leukaemia Group (CCLG)

Tel **0333 0507 654**
Email **info@cclg.org.uk**
www.cclg.org.uk
Leading children's cancer charity, and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer.

General health information

Health and Social Care in Northern Ireland

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

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88** (7 days a week, 8am to 8pm)
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

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.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'Therapist directory' page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955** (Mon to Fri, 9am to 5pm)
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**
Email **info@mind.org.uk**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

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

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Disability and Carers Service

Tel **0800 587 0912** (Mon to Fri, 10am to 4pm)
Textphone **028 9031 1092**
nidirect.gov.uk/contacts/disability-and-carers-service
Manages Disability Living Allowance, Attendance Allowance, Carer’s Allowance and Carer’s Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

GOV.UK

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

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.gov.wales/find-your-local-authority

Macmillan Benefits Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

Email **info@moneyadvicescotland.org.uk**
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NI Direct

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Northern Ireland Housing Executive

Tel **03448 920 900** (Mon to Fri, 8.30am to 5pm)
Textphone **18001 03448 920 900**
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**
Email **contactus@redcross.org.uk**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
Email **enquiries@disabilityrightsuk.org**
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Living Made Easy

Helpline **0300 999 0004** (Mon to Fri, 9am to 5pm)
Email **info@dlf.org.uk**
www.livingmadeeasy.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Scope

Helpline **0808 800 3333**
(Mon to Sat, 9am to 6pm, and Sun 10am to 6pm)
Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333.**
Email **helpline@scope.org.uk**
www.scope.org.uk
Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for Disabled people.

Support for older people

Age UK

Helpline **0800 055 6112** (Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm)
Email **helpline@lgbt.foundation**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients

www.outpatients.org.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

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

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

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
(Mon to Fri, 9am to 6pm)
Helpline (Northern Ireland) **028 9043 9843**
Email **advice@carersuk.org**
www.carersuk.org

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

Cancer registries

The cancer registry is 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 a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

www.digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
www.phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
www.qub.ac.uk/research-centres/nicr/AboutUs/Registry

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. 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: Mr Neil Barber, Consultant Urologist; Professor Tim Eisen, Professor of Medical Oncology; Dr Serena Hilman, Consultant Clinical Oncologist; Lucy Powell, Clinical Nurse Specialist; Dr Naveen Vasudev, Consultant Medical Oncologist; Deborah Victor, Clinical Nurse Specialist; Dr Tom Waddell, Consultant Medical Oncologist; and Paolo Zabat, 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 **informationproductionteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our kidney cancer information. If you would like further information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

Escudier B et al. Renal cell carcinoma: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. 2019. Annals of oncology 30. [Accessed April 2021.]

European Association of Urology. Renal cell carcinoma guidelines: EAU Guidelines. Edn. presented at the EAU Annual Congress Milan 2021. [Accessed April 2021.]

National Institute for Health and Care Excellence (NICE). Nivolumab with ipilimumab for untreated advanced renal cell carcinoma: technology appraisal guidance (TA581). 2019. [Accessed April 2021.]

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here to support them every step of the way.

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

5 ways you can help someone with cancer

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

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

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

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

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

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

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Mr/Mrs/Miss/Other

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Surname

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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 would rather donate online go to **macmillan.org.uk/donate**

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Please cut out this form and return it in an envelope (no stamp required) to: Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

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

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

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** 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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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