

# 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. Some of the information may be useful if you have another type of kidney cancer. But check with your cancer team. There is also information for carers, family members and friends.

The booklet explains the treatments you might have. It also has information about how to get advice and support about feelings, relationships, work and money (pages 99 to 110).

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.

This booklet does not have information about kidney cancer risk factors, signs and symptoms or tests to diagnose kidney cancer. You can find more information about these on our website. Visit **macmillan.org.uk/**kidney-cancer

We also have separate information on our website about 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). It develops and is treated in a different way to kidney cancer. Visit **macmillan.org.uk/utuc** 

Rarely, very young children and adults develop a type of kidney cancer called Wilms' tumour or nephroblastoma. The Children & Young People's Cancer Association (CCLG) has more information about Wilms' tumour – page 118.

### 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 118 to 131, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse on page 132.

## Quotes

In this booklet, we have included quotes from people who have had kidney cancer or cared for someone who did, which you may find helpful. These 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** 

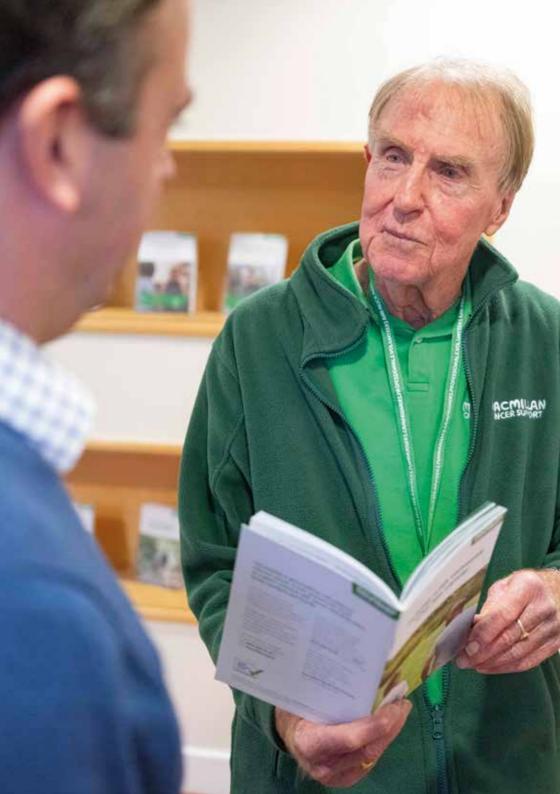
If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are 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, easy read, Braille, large print, interactive PDFs and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

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# Finding out you have kidney cancer

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis may have been unexpected. For example, sometimes cancer is found during a scan for another reason. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with kidney cancer. We have more information about possible causes, risk factors and symptoms of kidney cancer at **macmillan.org.uk/kidney-cancer** 

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment you will have. You might choose to spend some time reading about the cancer. Or you may prefer to wait until you meet with your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on the Macmillan Support Line. They will be able to talk to you about what has happened and any worries you have.

Call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm.



# Macmillan Cancer Information and Support Centre

Welcome to the Queens Hospital

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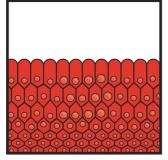
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# What is cancer?

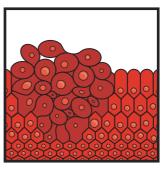
Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets 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 is called a benign tumour. It 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 is called a malignant tumour. It 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 (pages 14 to 15). 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.

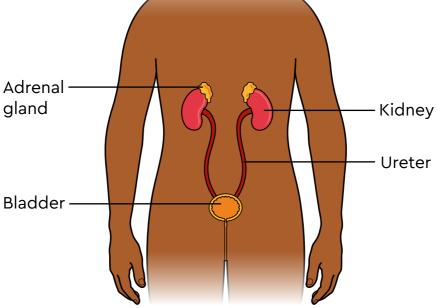
# The kidneys

Most people have 2 kidneys. They sit in the tummy (abdomen), towards the back of the body. There is 1 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 made into urine (pee).

On top of each kidney is a small gland called the adrenal gland. This makes hormones. A layer of fat surrounds the kidneys and adrenal glands. This is contained in a capsule of fibrous tissue (pages 12 to 13).





## How the kidneys work

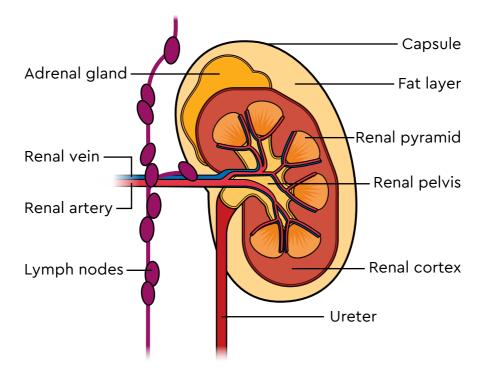
The kidneys clean the blood and keep anything the body needs. This helps control the balance of fluid, salt and minerals in the body. It also helps maintain blood pressure.

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 clean the blood by removing waste products and extra water. This is then turned into urine. The filtered blood goes back to the rest of the body through the renal veins.

The urine collects in the middle of each kidney in an area called the renal pelvis. Urine drains from the kidneys through long, muscular tubes called ureters. Each kidney has a ureter that connects to the bladder. Urine is stored in the bladder before it leaves the body through a tube called the urethra.

### The structure of the kidney

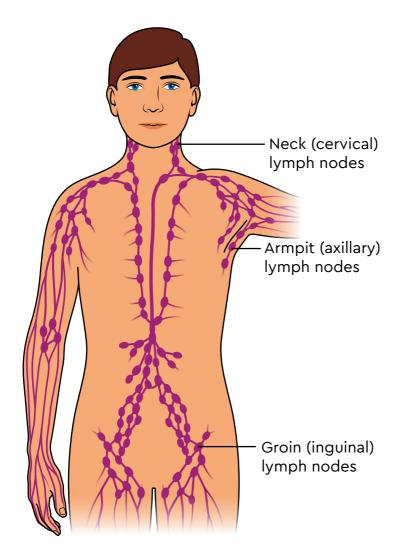


# The lymphatic system

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 lymph nodes in the body

# **Kidney cancer**

Each year, over 13,000 people in the UK are diagnosed with kidney cancer.

Kidney cancer usually only affects 1 kidney. But occasionally it affects both kidneys. This is called bilateral kidney cancer. It is more common in people who have a genetic condition linked to kidney cancer.

## **Types of kidney cancer**

There are different types of kidney cancer.

#### Renal cell cancer (RCC)

About 8 out of 10 kidney cancers (80%) are renal cell cancers or RCCs. They start in the main outer area of the kidney called the renal cortex (page 13).

There are different types of RCC, including:

- clear cell RCC this is the most common type
- papillary RCC
- chromophobe RCC.

#### Upper urinary tract urothelial cancer (UTUC)

Upper urinary tract urothelial cancer (UTUC) is a type of cancer that sometimes affects the area of the kidney called the renal pelvis (page 13). This is sometimes called transitional cell carcinoma.

Although it may start in the kidney, UTUC develops differently and is treated differently to other types of kidney cancer. We have separate information about treating UTUC. Visit **macmillan.org.uk/utuc** 

#### **Rarer renal cell cancers**

There are other very rare types of renal cell cancer:

- Renal medullary cancer (RMC) is a fast-growing cancer linked to a blood condition called sickle cell disease.
- Collecting duct cancer (CDC) is a cancer with features of both RCC and UTUC.

These types may be treated differently to other types of RCC. Your doctor can give you more information about RMC or CDC.

Occasionally, other types of cancer are found in the kidney – for example, lymphoma or sarcoma. These are not types of kidney cancer and may be treated differently.

We have more information about these types of cancer online:

- macmillan.org.uk/lymphoma
- macmillan.org.uk/sarcoma

# **Staging and grading**

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

- the type of kidney cancer (pages 16 to 17)
- the stage of cancer this describes its size and whether it has spread (pages 18 to 22)
- the grade of cancer this gives an idea of how quickly the cancer might grow and spread (page 22).

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

- T describes the size of the tumour.
- N describes whether the cancer has spread to the lymph nodes.
- 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.

#### Т3

T3 means the cancer is growing into the fat around the kidney, or into the renal vein or vena cava (page 13). These are major veins close to the kidney. The cancer 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.

#### Т4

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, this may be the bones, liver, brain, lungs 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. The number stages range from 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 1 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 this is a small cancer that has not spread.
- Locally advanced this is cancer that has started to spread into surrounding tissues or nearby lymph nodes, or both.
- Local recurrence this is cancer that has come back in the same area after treatment.
- Secondary, advanced, widespread or metastatic this is cancer that has spread to another part of the body.

# **Grading of kidney cancer**

A doctor decides the grade of the cancer by checking 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 3. But sometimes a 1 to 4 system called the Fuhrman system is used. 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 (page 131).



# Planning treatment for kidney cancer

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# **Treatment overview**

Treatment for kidney cancer depends on a number of factors, including:

- the position of the cancer
- the type of kidney cancer (pages 16 to 17)
- the stage of the cancer (pages 18 to 22)
- the grade of the cancer (page 22).

This information is about the most common type of kidney cancer, called renal cell cancer (RCC). Some of the information may be useful if you have a rarer type of kidney cancer. But you should check with your cancer team.

Your cancer team plan your treatment carefully. They will also consider:

- how well your kidneys work
- your general health
- your wishes.

Research is being carried out to find more effective treatments for kidney cancer. You may be invited to take part in a clinical trial for a new drug or treatment (pages 88 to 89).

## **Early kidney cancer**

Cancer that has not spread outside the kidney (stage 1 or 2) is usually treated with surgery – pages 36 to 49. If the cancer is small, the surgeon may only remove the part of the kidney with cancer. If the cancer is bigger, they may need to remove the whole kidney. Surgery may be the only treatment you need.

Tumour ablation treatment (pages 50 to 57) is sometimes used instead of surgery for early kidney cancer. This is when cancer cells are destroyed using very high or low temperatures, or radiotherapy. This treatment can be useful if:

- you cannot have surgery or do not want it
- it is important to try and keep the affected kidney for example, if you only have 1 kidney.

Some people have regular scans to monitor a small kidney cancer instead of any treatment. This approach is called monitoring or active surveillance (pages 62 to 63). If the cancer shows signs of growing, then treatment may start.

If you have a genetic condition called von Hippel-Lindau disease (VHL), you may have a targeted therapy called belzutifan instead of surgery (pages 64 to 73). This can control a small early kidney cancer.

## Locally advanced kidney cancer

Surgery is often the main treatment if the cancer has spread into surrounding tissues or nearby lymph nodes or veins but not to other parts of the body. We have more information about this on pages 36 to 49.

You may also have an immunotherapy drug called pembrolizumab after surgery (pages 74 to 83). This helps reduce the risk of the cancer coming back. Other drugs may be used before or after surgery as part of a clinical trial (pages 88 to 89).

We have more information about clinical trials on our website. Visit **macmillan.org.uk/clinical-trials** 





## Advanced (metastatic or secondary) kidney cancer

Cancer drugs are the main treatment for advanced kidney cancer. The 2 types of treatment are targeted therapy and immunotherapy (pages 64 to 83). You may have a combination of drugs or 1 drug on its own. The aim is to:

- try to control the cancer
- reduce symptoms
- improve your quality of life.

Several different drugs are available. If 1 combination stops working, your cancer team may suggest trying a different drug or combination of drugs.

Other treatments may also be used. These will not cure the cancer. But for some people, it can mean they are likely to live longer. They include:

- surgery to remove the kidney (page 37)
- arterial embolisation (pages 58 to 61)
- radiotherapy (pages 84 to 87).

If there is a secondary cancer in only 1 area of the body, you may have radiotherapy or surgery to treat that area (page 43) – for example, the lung or a bone.

Some advanced kidney cancers grow very slowly. If the cancer is growing slowly and not causing symptoms, your cancer team may suggest regular scans to check the cancer for a while before starting treatment. This is called monitoring or active surveillance (pages 62 to 63).

# How your treatment is planned

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

- A urologist is a surgeon who treats problems of the urinary system and specialises in treating kidney cancer.
- An oncologist is a doctor who treats people who have cancer.
- A urology clinical nurse specialist (CNS) is a nurse who gives information about kidney cancer, and support during treatment.
- A radiologist is a doctor who looks at scans and x-rays to diagnose problems and performs tests and procedures.
- A pathologist is 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 (pages 88 to 89).

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.

Writing down your questions before meeting your doctor or nurse may help. You may find it helpful to bring someone with you to meetings. They may be able to take notes or can help you remember what was said.

If you feel you cannot decide on your treatment once it has been explained to you, you can 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 1 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 on 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 have treatment.

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 (page 31).

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 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 cancer 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 cancer 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 meet with 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** 





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## Surgery

Surgery may be the only treatment you need. The type of surgery (operation) you have will depend on your general health and the stage of the cancer – pages 18 to 22. 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. You may also have it for larger kidney cancers. Your doctor will explain whether it is right 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 keep working.

You may have this operation to try and keep the affected kidney. This may be because:

- your other kidney does not work well
- you have kidney disease or other conditions that may affect how your kidneys work in the future.

If you have a type of kidney cancer that has been passed to you from a parent (inherited), 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 means you may have to travel for treatment.

## Removing the whole kidney

This operation is called a radical nephrectomy. You may have this operation if it is not possible to take only part of the kidney. For example, you have this operation if the cancer is:

- affecting a large part of the kidney
- in the middle of the kidney.

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 (pages 14 to 15).

You can usually live a normal life with 1 kidney. It can do the work of both kidneys. The surgeon can talk to you about this before you decide whether to have surgery.

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

If there is cancer in 1 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 may help them live longer. Your treatment plan will usually include other treatments such as immunotherapy (pages 74 to 83) and targeted therapy (pages 64 to 73).

You may need to think about 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.

## **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. You usually have a general anaesthetic for kidney cancer surgery.

Kidney cancer surgery is often done as keyhole surgery (pages 40 to 41), but open surgery is sometimes needed (page 42).

#### 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.

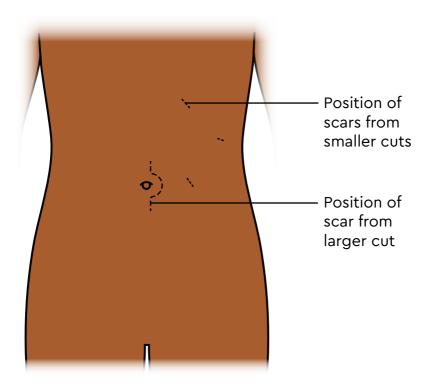
The surgeon starts by making 3 or 4 small cuts in the tummy. The laparoscope then goes through 1 of the small cuts in the skin. The tummy will be inflated with gas to help the surgeon operate more easily.

During the operation, the surgeon puts the kidney they want to remove into a bag inside the body. At the end of the operation, they will remove the bag with the kidney inside by either:

- making 1 of the cuts bigger
- adding an extra cut.

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 surgery scars



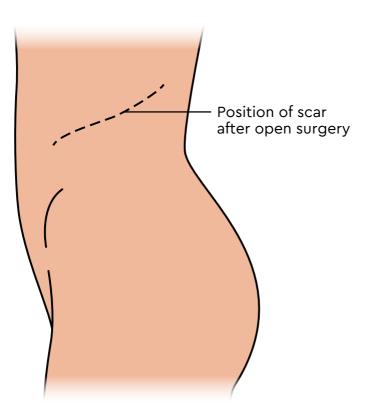
#### Robot-assisted keyhole surgery

The surgeon may use a specialised machine to help with keyhole surgery. The surgeon controls the instruments that are attached to the machine. 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 1 large cut 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 1 place in the body, such as the lung or brain. It is also important that you are well enough for the operation.

Removing a secondary cancer will not usually cure the cancer, but it 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. Your cancer team can explain whether removing the secondary cancer may help you.

## 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 meet with 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 talk about any concerns you may have. It is important you understand everything about the operation you are having. You will meet with 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 reduce the amount before your operation. This will help lower the 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 stop smoking. A stop smoking organisation can also give you advice (pages 122 to 123).

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

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

## After your operation

Your recovery after surgery depends on the type of operation you had.

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, a nurse will take it 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 removing 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 40 to 41), 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 1 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 you take orally.

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.

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 shortly after your operation. The hospital ward staff will help you with this. They can help you wash and use the toilet. When you are moving about more easily, 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 a 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 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 (page 42), the surgeon will close the wound using staples or stitches. 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 your arms or legs
- 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 (page 42), 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 had 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 they have recovered after about 12 weeks.

You will not be able to do some everyday activities while you recover. For example, you may not be able to shop, drive, have sex, play sports or work. Your nurse or surgeon can tell you when you will be able to do these things again.

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 ask questions, or 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 4cm.

You may have this treatment if:

- you have a small tumour and are not well enough for surgery
- you choose not to have surgery
- it is important to try to keep the affected kidney, or you only have 1 kidney
- you have a type of kidney cancer that causes lots of tumours and was passed down from a parent (inherited)
- cancer is affecting both kidneys.

Tumour ablation generally causes fewer side effects and has a quicker recovery time than surgery for kidney cancer. With both surgery and tumour ablation there is a small risk that not all the cancer is removed. This risk is a little higher for tumour ablation. If tumour ablation is an option for you, your cancer doctor will talk to you about:

- the risks of tumour ablation
- the benefits of avoiding surgery
- the benefits of keeping the kidney.

There are different types of tumour ablation. The 2 most common treatments are:

- cryotherapy this uses liquid nitrogen to freeze the tumour (page 54)
- radiofrequency ablation (RFA) this uses an electric current to produce high temperatures to destroy the tumour (page 55).

Other types of tumour ablation may be used in clinical trials (pages 88 to 89). These include:

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

Your cancer doctor or specialist nurse will talk to you about which of these methods may be right for you.

You should have a guided biopsy to collect a tissue sample. This is to give your doctor more information about the cancer. It may be done before tumour ablation, or your doctor may decide to take a sample during treatment.

We have more information about having a kidney biopsy on our website. Visit **macmillan.org.uk/** kidney-cancer

## How tumour ablation is done

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

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

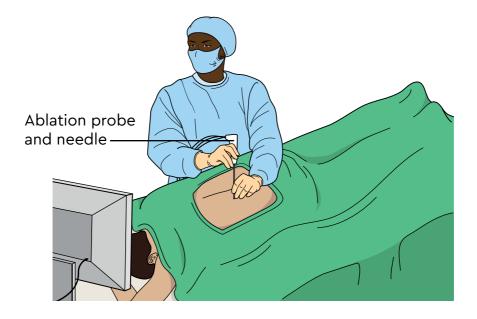
The doctor uses a local anaesthetic to numb the area around the kidney. Then you have an ultrasound or CT scan. These scans guide the doctor to the right area of the kidney. The scans also help them monitor what is happening during your treatment.

We have more information about these scans on our website:

- macmillan.org.uk/ultrasound
- macmillan.org.uk/ct-scan

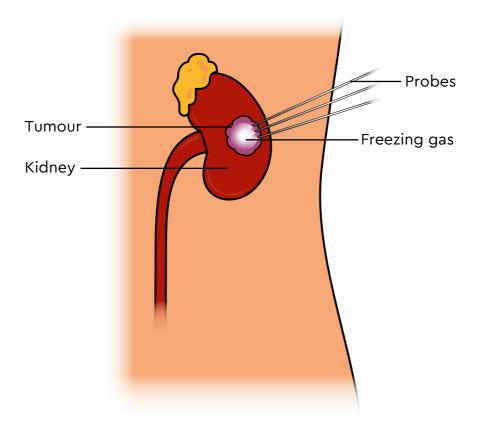
When the doctor identifies the tumour on the monitor, they place 1 or more fine probes through the skin (percutaneously) into the tumour.

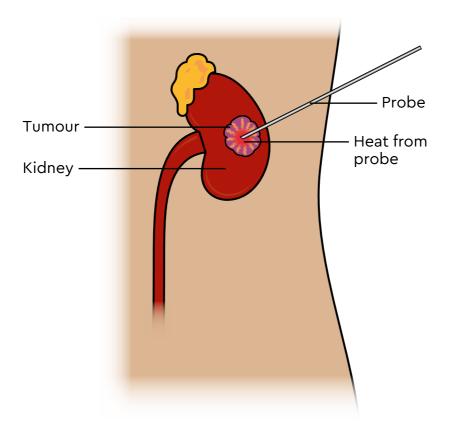
### Having tumour ablation



The probes freeze or heat the tumour (pages 54 to 55). 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 tumour ablation is done using keyhole surgery (pages 40 to 41). You have a general anaesthetic for keyhole surgery. The surgeon makes a few small cuts in your tummy (abdomen) and passes a laparoscope through 1 of the cuts to look at the tumour.

A laparoscope is a thin tube with a light and a camera on the end. It 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 where you had the treatment. 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 usually need to stay in a hospital bed for 4 to 6 hours after the treatment.

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

## **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 treatment and for a few hours afterwards
- a narrowing of the ureter this can affect how urine drains from the kidney (pages 12 to 13).

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 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 check the result of the treatment.

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.

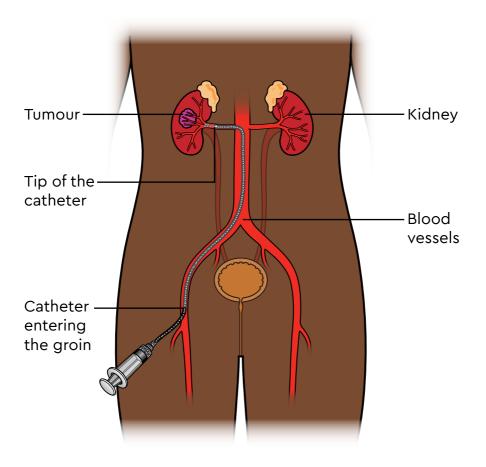
You may be offered arterial embolisation if an operation is not possible for you.

## How arterial embolisation is done

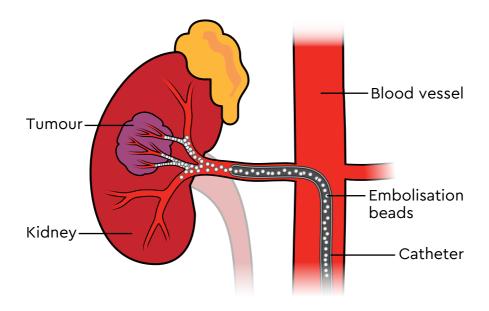
Before treatment, the nurse or doctor usually gives you a mild sedative to help you relax. They then inject some local anaesthetic into the skin at the top of the leg (the groin) to numb the area.

A doctor puts a thin, plastic tube (catheter) into a blood vessel in the groin. They guide the catheter using the x-ray images to help. They continue upwards until the tip reaches the artery that carries blood to the area of the kidney with the cancer. 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 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 feel tired.

## Going home after arterial embolisation

After arterial embolisation, you may need to stay in hospital overnight, or for 1 or 2 days. 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 also arrange for you to have a CT scan to check the result of the treatment.

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

## Monitoring

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

During monitoring, you have regular ultrasounds, CT scans 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.

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.

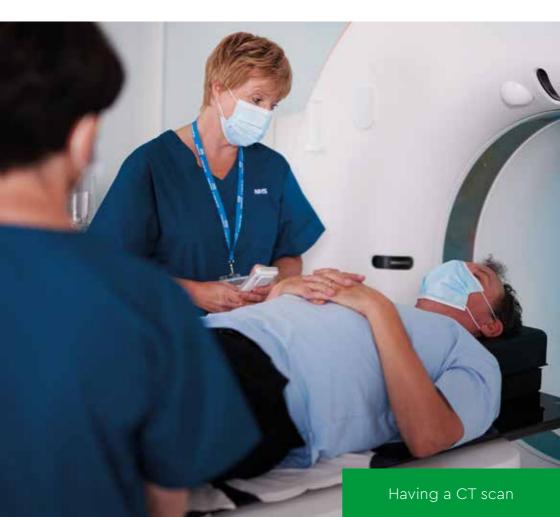
The main advantage of monitoring is that you can avoid the risks or side effects of treatment.

Monitoring may be an option for people with very small, slow-growing kidney cancers (under 4cm). It is usually offered to people who 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 (pages 64 to 83).

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. 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 (page 100). You could talk to family or friends, keep a journal or join a support group. Our Online Community also has a kidney cancer group. Visit **macmillan.org.uk/community** 



## **Targeted therapy**

Targeted therapies are a type of cancer drug. They target something in or around the cancer cell that is helping it grow and survive.

Targeted therapy drugs are often used to treat kidney cancer that has spread to other parts of the body. This is called advanced or metastatic kidney cancer. The aim of targeted therapy is to control the cancer for as long as possible.

You may have a targeted therapy drug on its own or in combination with other types of drugs, such as immunotherapy (pages 74 to 83). Your cancer team will explain your treatment and which drugs are suitable for you.

If you have a genetic condition called von Hippel-Lindau disease (VHL), you may have a targeted therapy called belzutifan instead of surgery. This can control a small early kidney cancer.

## Targeted therapy drugs for kidney cancer

The following targeted therapy drugs are used to treat kidney cancer:

- axitinib (Inlyta®)
- belzutifan (Welireg®)
- cabozantinib (Cabometyx®, Cometriq®)
- everolimus (Afinitor®)
- lenvatinib (Lenvima®, Kisplyx®)
- pazopanib (Votrient®)
- sunitinib (Sutent®)
- tivozanib (Fotivda®).

All these treatments are tablets or capsules that you take by mouth (orally). You will usually continue taking a targeted therapy drug as long as it keeps the cancer under control. You will have regular CT scans to check this.

Targeted therapy drugs often have several names, which can be confusing. Your cancer team might use 1 of the names above. These are the official names of drugs and some of their brand names.

Or your cancer team might use 1 of the following terms. These describe how different types of targeted therapy drug work inside your body:

- tyrosine kinase inhibitor (TKI)
- mTOR inhibitor
- small molecule inhibitor.

We have more information about individual targeted therapy drugs on our website. Visit **macmillan.org.uk/treatments-and-drugs** 

#### Intermittent targeted therapy

Most targeted therapy drugs are taken every day. Some drugs, such as sunitinib or tivozanib, are taken for a number of weeks followed by a break of several weeks. Your cancer team will explain when to take the drug you have.

Your cancer team may suggest short breaks in your treatment to help manage side effects. For example, you may take the drug for 5 days and then have 2 days off, before taking the drug again.

Always follow your cancer team's advice about how to take your treatment.

## Side effects of targeted therapy

Each targeted therapy drug has its own side effects. We have detailed information about individual targeted therapy drugs and their side effects on our website. Visit **macmillan.org.uk/treatments-and-drugs** 

Your cancer team 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 side effects.

Your cancer team will give you contact numbers and a 24-hour number for the hospital. If you feel unwell or need advice, you can call at any time of the day or night. Save these numbers in your phone or keep them somewhere safe.

It is important to tell your cancer team 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.

#### Feeling tired (fatigue)

Feeling tired is a common side effect of this treatment. It may build up while you are taking the drug and improve gradually if you have a break from treatment. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can help you feel less tired.

If you feel sleepy, do not drive or use machinery.

#### Sore mouth and throat

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

Contact the hospital straight away on the 24-hour number, if:

- a sore mouth or throat affects how much you can drink or eat
- your mouth, tongue, throat or lips have any blisters, ulcers or white patches.

They can give you advice, and mouthwash or medicines to help with the pain or to treat any infection. Follow their advice and make sure you:

- drink plenty of fluids
- avoid alcohol and tobacco
- avoid food or drinks that irritate your mouth and throat.

#### Diarrhoea

Some treatments may cause diarrhoea. Diarrhoea means passing more stools (poo) than is normal for you, or having watery or loose stools. You may also have stomach cramps. If you have a stoma, it may be more active than usual.

If you are passing loose stools 3 or more times a day and this is not normal for you, contact the hospital as soon as possible on the 24-hour number. Follow the advice they give you about:

- whether to take anti-diarrhoea medicines
- drinking enough fluids to keep you hydrated and to replace lost salts and minerals
- any changes to your diet that might help.

They might also ask you for a specimen of your stool to check for infection.

#### Skin changes

Some targeted therapy drugs can affect your skin. It might feel dry. You may develop a rash, which may be itchy. Always tell your doctor, nurse or pharmacist about any skin changes. They can give you advice or prescribe creams or medicines to help. If your skin feels dry, try using soap-free cleansers and unperfumed moisturising cream every day.

Some drugs can affect the palms of your hands and the soles of your feet. This is called palmar-plantar or hand-foot syndrome. If you have white skin, these areas may become red. If you have black or brown skin, these areas might get darker.

The skin on the palms of your hands and the soles of your feet may:

- be sore
- be painful, tingle, or swell
- peel, crack or blister.

If you have any of these symptoms, contact the hospital straight away on the 24-hour number for advice. This is especially important if you have any broken skin or if walking is difficult. They can prescribe creams and painkillers to help.

#### High blood pressure

Some drugs cause high blood pressure (hypertension). You may be given medication to help manage this. You will have your blood pressure checked regularly and may be shown how to check it at home. "Ruby has 'braved the shave' and joined the 'bald is beautiful' club. In true Ruby style, she didn't bat an eyelid at her head being shaved, and has embraced her new look! "

Katie, whose daughter Ruby was diagnosed with kidney cancer

#### Hair loss

You might notice that your hair slowly gets thinner. But you are very unlikely to lose all the hair from your head. Your hair can also become more brittle. The colour or texture of your hair might change while taking a targeted therapy drug.

Your hair will usually go back to normal after treatment ends. Your nurse can give you information about coping with hair loss. We have more information in our booklet and audiobook **Coping with hair loss** (page 112).

#### Thyroid changes

Some targeted therapy drugs can affect the thyroid gland. You will have regular blood tests during your treatment to check how well your thyroid is working. Possible symptoms of thyroid changes include:

- tiredness
- feeling depressed
- difficulty concentrating
- weight gain
- constipation
- feeling cold
- dry skin
- dry hair.

Tell your cancer team if you notice any of these symptoms.

#### Slow wound healing

Wounds may take longer to heal while you are taking targeted therapy. If you have surgery (pages 36 to 49), you may need to stop taking your treatment before it and for a few weeks afterwards. Your cancer team will give you more advice.

#### **Raised blood sugar levels**

Some targeted therapy drugs may raise your blood sugar levels. You will have regular blood tests to check this. Symptoms of raised blood sugar include:

- feeling thirsty
- needing to pass urine (pee) more often
- feeling tired.

If you have these symptoms while having this treatment, tell your doctor or nurse.

If you have diabetes, your blood sugar levels may be higher than usual. Your doctor will talk to you about how to manage this.

#### **High cholesterol**

Everolimus can increase the amount of cholesterol (fats or lipids) in your blood. Your doctor will take blood tests during your treatment to check for this.

#### Feeling sick

Some people may feel sick during targeted therapy treatment. Your doctor, nurse or pharmacist can prescribe anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as they tell you to.

If you feel sick, take small sips of fluid often and eat small amounts regularly. It is important to drink enough fluids.

Contact the hospital on the 24-hour number as soon as possible if you:

- continue to feel sick
- are sick (vomit) 1 to 2 times in 24 hours.

They will give you advice. They may change your anti-sickness treatment. Let them know if you still feel sick.

# Immunotherapy

Immunotherapy drugs encourage the body's immune system to find and attack cancer cells.

This type of cancer drug can be used for the following reasons:

- Immunotherapy may be used after surgery to remove locally advanced kidney cancer. You may have a drug called pembrolizumab to reduce the risk of cancer coming back again.
- Immunotherapy can be used to treat kidney cancer that has spread to other parts of the body (advanced or metastatic kidney cancer). The aim is to control the cancer for as long as possible. You may have an immunotherapy drug in combination with a targeted therapy drug to start with (pages 64 to 73). Or you may have immunotherapy on its own.

Your cancer team will explain your treatment and which drugs are suitable for you. We have detailed information about individual immunotherapy drugs and their side effects on our website. Visit macmillan.org.uk/treatments-and-drugs

### Immunotherapy drugs for kidney cancer

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

- avelumab (Bavencio®)
- ipilimumab (Yervoy®)
- nivolumab (OPDIVO®)
- pembrolizumab (Keytruda®).

These drugs are usually given as a drip into a vein (intravenously). You usually have 1 dose every few weeks. Your cancer team can explain how many doses you may need and how often you may need them.



### Side effects of immunotherapy

Checkpoint inhibitors make the immune system more active. This helps them find and attack cancer cells. But this can also cause side effects called immune-related side effects.

Immune-related side effects are different to the side effects of other cancer drugs or treatments. They are caused by the immune system attacking normal cells in the body as well as cancer cells.

This type of side effect can affect any part of the body. But your cancer team will explain your treatment and any important side effects you should know about.

Immune-related side effects may:

- be mild to start with
- quickly become serious unless treated
- start during treatment
- start weeks, months or sometimes more than 1 year after treatment ends.

Some of these side effects are rare. But it is important to know about them and to get advice if you experience any side effects during or after treatment.

If you have any of the symptoms or side effects on the next few pages, contact the hospital straight away on the 24-hour number. Do not try to treat this type of side effect yourself.

Your team will also give you a card with information about your treatment. It is important to keep the card with you during and after treatment. You should show it to any doctor or healthcare professional caring for you.

#### Skin changes

This treatment may cause inflammation in the skin. This is usually mild, but if it is not treated it can become serious. You may need creams, steroids or other medicines to treat skin problems.

If you notice skin changes during treatment, or after treatment ends, contact the hospital on the 24-hour number as soon as possible.

Skin changes can include:

- a rash or bumps on the skin
- dry or itchy skin
- patches of white or paler skin.

To protect your skin from the sun, use suncream of at least SPF 30. SPF stands for sun protection factor. Cover up with clothing and a hat.

Contact the hospital straight away on the 24-hour number if you have any of these symptoms:

- a rash that is spreading
- blistering or peeling skin
- flu-like symptoms, such as a high temperature and joint pain.

These symptoms can be a sign of a serious skin reaction that needs to be treated immediately in hospital.

#### Diarrhoea or tummy pain

You may have diarrhoea or tummy (abdominal) pain. This treatment can also cause inflammation of the bowel (colitis), which can be very serious.

Diarrhoea means passing more stools (poo) than is normal for you, or having watery or loose stools. If you have a stoma, it may be more active than usual.

Contact the hospital straight away on the 24-hour number if you have any of the following symptoms during or after treatment:

- You have diarrhoea 4 or more times in a day.
- You have a moderate increase in stoma activity.
- You have uncomfortable tummy cramps.
- You have diarrhoea at night.
- Your temperature is over 37.5°C.
- There is blood or mucus in your stool.

You may need to go into hospital to have fluids through a drip or treatments such as steroids.

#### Hormone changes

This treatment may affect your hormones. Hormones control many different processes in the body. You will have regular blood tests to check some of your hormone levels.

Contact the hospital on the 24-hour number if you have any of these side effects during treatment or after it ends:

- increased sweating
- weight gain or weight loss
- dizziness or fainting
- feeling more hungry or thirsty than usual
- loss of sex drive
- passing urine (peeing) more often than usual
- headaches that do not go away
- feeling more tired than usual (fatigue)
- mood changes.

You may need drugs to control your hormone levels.

#### Muscle and joint pain

This treatment can cause sore or weak muscles. Your joints may also be stiff, sore or swollen (arthritis). If you already have problems with joint pain, this may become worse.

Contact the hospital on the 24-hour number if you have any of these symptoms during treatment or after it ends:

- new or worsening aches or pains
- new or worsening stiffness in a joint
- swollen joints.

You may need steroids or other treatments, such as painkillers.

#### Effects on the lungs

This treatment can cause inflammation of the lungs. This is called pneumonitis. Contact the hospital straight away on the 24-hour number if you notice any of these changes during treatment or after it ends:

- breathlessness
- a cough that does not go away
- wheezing
- a fever, with a temperature over 37.5°C.

You should also tell the hospital if any existing breathing problems get worse. You may have tests to check your lungs. You may need steroids or other treatments.

#### Effects on the liver

This treatment can cause liver inflammation and may affect how your liver works. This is called hepatitis. You will have regular blood tests to check this. If the blood tests show liver changes, you may have steroids.

Sometimes liver changes can be serious. Contact the hospital straight away on the 24-hour number if you have any of these symptoms during treatment or after it finishes:

- yellow skin or eyes
- feeling very sleepy
- dark urine (pee)
- unexplained bleeding or bruising
- pain in the right side of your tummy (abdomen)
- loss of appetite.

If you have black or brown skin, yellowing of the skin can be hard to notice. You might notice yellowing of the whites of your eyes or a change in the colour of your urine first.

#### Effects on the heart

This treatment can affect how the heart works. This is not common, but it can be serious. You may have tests to check how well your heart is working. These may be done before, during and after treatment.

Contact the hospital straight away on the 24-hour number if you have any of these symptoms during or after treatment:

- breathlessness
- dizziness
- changes to your heartbeat
- swollen feet and ankles.

Other conditions can cause these symptoms, but it is important to get them checked by a doctor.

Always call 999 if you have:

- chest pain, pressure, heaviness, tightness or squeezing across the chest
- difficulty breathing.

If your symptoms are caused by this treatment, you may need steroids. You may be monitored in hospital for a time.

#### Effects on the nervous system

Rarely, this treatment can affect the brain and nerves. These effects may be mild at first, but can become serious if they are not treated. Contact the hospital straight away on the 24-hour number if you have any of these symptoms during treatment or after it ends:

- any weakness, numbness or tingling in your arms, legs or face
- a headache that does not get better
- dizziness
- drowsiness or confusion
- problems with moving or speaking
- any unexplained pain in other parts of your body.

You may need steroids and other treatments.

# Radiotherapy

Radiotherapy uses high-energy rays called radiation to treat cancer. It destroys cancer cells in the area being treated.

Radiotherapy is sometimes used to treat early kidney cancer if surgery is not an option. Usually a type called stereotactic ablative body radiotherapy (SABR), or stereotactic body radiation therapy (SBRT), is used. This treatment targets the cancer very precisely. High doses of radiotherapy can be given to very small areas.

Radiotherapy can also be given to control kidney cancer and treat any symptoms. This is called palliative treatment. Palliative radiotherapy may help control the cancer for longer when it is not possible to cure it.

Palliative radiotherapy might be used to treat:

- symptoms of kidney cancer such as bleeding
- cancer that has spread to other parts of the body such as the lung, brain or bones.

### Planning your radiotherapy treatment

A team of experts carefully plans your radiotherapy so it does as little harm as possible to normal cells.

You will have a hospital appointment to plan your treatment. You will usually have a CT scan of the area to be treated. Some people have an MRI or a PET scan. During the scan, you need to lie in the position you will be in for all your radiotherapy treatments.

Your radiotherapy team uses information from this scan to plan:

- the dose of radiotherapy
- the area to be treated.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They are made in the same way as a tattoo. The marks help the radiographer position you correctly for each radiotherapy session.

These marks will only be made with your permission. If you are worried about them or already have a tattoo in the treatment area, tell your radiographer. They can discuss this with you.

#### Having radiotherapy treatment

Radiotherapy is normally given in a number of short, daily treatments in a hospital radiotherapy department. A radiotherapy machine aims high-energy rays at the area of the body being treated.

This type of radiotherapy is also called external beam radiotherapy. We have more information about external beam radiotherapy on our website. Visit **macmillan.org.uk/external-beam-radiotherapy** 

You usually have radiotherapy as an outpatient. You sometimes have it during a hospital stay. Usually, each appointment takes about 10 to 30 minutes. Your radiotherapy team will explain how many treatments you will have and when you will have them. Your course of treatment may last up to a few weeks.

The person who operates the machine is called a radiographer. They give you information and support during your treatment.



At the beginning of each session, the radiographers will make sure you are in the correct position. They will tell you how long your treatment will take. When everything is ready, they leave the room and treatment starts. The treatment itself is not painful. It does not make you radioactive. You will not be a risk to anyone during the course of your treatment.

The radiographers can see and hear you from outside the room. There is usually an intercom, so you can talk to them if you need to during your treatment.

During treatment, the radiotherapy machine may stop and move into a new position. This is so you can have radiotherapy from different directions.

### Side effects of radiotherapy

Some normal cells in the area being treated can also be damaged by radiotherapy. This can cause side effects. As the normal cells recover, the side effects usually get better.

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. Side effects usually go away slowly when your course of treatment has finished. You should tell your doctors if they continue.

We have more information in our booklet and audiobook **Understanding radiotherapy** (page 112).

# **Clinical trials – research**

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about cancer clinical trials on our website. Visit **macmillan.org.uk/clinical-trials** 



### Taking part in a clinical 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.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part – pages 32 to 33. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.



# After your treatment

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# Follow-up

After your treatment has finished, you will have regular check-ups with your cancer doctor, urologist or nurse. They will let you know how often and 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 and CT scans or chest x-rays. These tests check how well your kidney or kidneys are working. They also 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. 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 for free on the Macmillan Support Line. Some other organisations also offer support to people affected by kidney cancer (pages 118 to 119).

Call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm.



# Wellbeing 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 (page 100). 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 wellbeing. 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.

# Living with 1 kidney

If you have had part or all of a kidney removed, your remaining kidney tissue and other kidney will usually be able to do the work of both kidneys. Your cancer team can check this with regular blood tests.

The lifestyle changes below can help you protect your remaining kidney or kidneys. This is because they help reduce your risk of:

- high blood pressure
- heart problems
- diabetes.

If you have any of these conditions, it is important to manage them. This is because they can put strain on the kidneys and may eventually cause damage.

### Stop smoking

If you smoke, stopping 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.

Using a stop smoking service improves your chances of success (pages 122 to 123). Your GP can also give you support and advice.

### 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. We have more information in our booklet and audiobook **Healthy eating and cancer** (page 112).

# 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

Sensible drinking guidelines recommend that you should not regularly drink more than 14 units of alcohol in a week. Try to have a few alcohol-free days each week. Drinkaware has more information about alcohol and drinking guidelines (page 121).

#### 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.

We have more information in our booklet **Physical activity and cancer** (page 112).

"We took up dancing a couple of years before treatment and we danced on the Sunday before surgery. Getting back to the dance floor was about avoiding the spiral of depression, restoring fitness and getting back to normal.

Peter, diagnosed with kidney cancer

#### **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 any:

- medicines you buy in a shop, pharmacy or online
- 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 (peeing)
- feeling you have to pass urine urgently.



# Your feelings and relationships

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# **Your feelings**

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet and audiobook **How are you feeling? The emotional effects of cancer** (page 112).

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups** Or talk to other people on our Online Community at **macmillan.org.uk/community** 

There is more information on pages 114 to 117 about other ways we can help you.



# Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships in our booklets:

- Talking about cancer
- Cancer and relationships: support for partners, families and friends this is also available as an audiobook.

We also have more information online at macmillan.org.uk/relationships

# 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 can support the person with cancer by listening and talking with them.

We have more information about supporting someone in our booklet and audiobook **Talking with someone who has cancer**.

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 and audiobook Looking after someone with cancer
- online at macmillan.org.uk/carers

### Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet and audiobook Talking to children and teenagers when an adult has cancer.

You can order our booklets and leaflets for free. Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.

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# Work and financial benefits

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# Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information about Statutory Sick Pay and benefits you may be entitled to on our website. Visit **macmillan.org.uk/sick-pay** 

We also have information for carers at macmillan.org.uk/carers

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has expert money advisers who can talk to you about your money worries, provide information about benefits and recommend other useful organisations that can help.

You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (pages 124 to 125).

Our booklet and audiobook **Help with the cost of cancer** has lots more information.

#### 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 on **0808 808 00 00**.

#### Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit **macmillan.org.uk/insurance-cancer** 

We have more information about travel insurance in our booklet and audiobook **Travel and cancer**. Our Online Community forum on travel insurance may also be helpful. Visit **macmillan.org.uk/community** 

You can order our booklets and leaflets for free. Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.

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# Work

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

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

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

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Our booklets have more information that may be helpful:

- Work and cancer
- Working while caring for someone with cancer
- Self-employment and cancer.

You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer**.

There is also lots more information online at **macmillan.org.uk/work** 

You can order our booklets and leaflets for free. Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.





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# **About our information**

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

# 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

- interactive PDFs
- large print
- British Sign Language
- translations.

• easy read booklets

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 want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

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.

To find out more about how we produce our information, visit **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 specialist nurses about things like diagnosis and treatments
- 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 find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to

# macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

# **Macmillan Information and Support Centres**

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

# 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. Please note the opening times may vary by service.

# **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 information to help you manage cancer at work. Visit **macmillan.org.uk/work** 

# 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 bring people together in their communities and online.

# Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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** 

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

# Macmillan healthcare professionals

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.

# 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

# **Action Kidney Cancer**

# Tel 0800 121 8721

# www.actionkidneycancer.org

Helps kidney cancer patients, families and friends join together and offer information, advice and friendship to each other.

# **Kidney Cancer UK**

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

# **Kidney Care UK**

# Support line **0808 801 0000** www.kidneycareuk.org

Practical, emotional and financial support for people with kidney conditions and their families.

# The Children & Young People's Cancer Association (CCLG)

# 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 cancer support organisations

# **Black Women Rising**

#### www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

#### **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** 

# www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

#### **Cancer Research UK**

#### Helpline 0808 800 4040 www.cancerresearchuk.org

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 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 300 0118 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.

# General health information

# Drinkaware

#### www.drinkaware.co.uk

Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

# Health and Social Care in Northern Ireland

# www.northerntrust.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 224 488 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-related and illness-related websites.

# Stop smoking services

# **NHS Smokefree Helpline (England)**

#### Tel 0300 123 1044

# www.nhs.uk/better-health/quit-smoking

Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

# **Quit Your Way (Scotland)**

#### Tel 0800 84 84 84

#### www.nhsinform.scot/quit-your-way-scotland

Scotland's national stop smoking support service. Offers advice and information about how to stop smoking. You can also chat online to an adviser.

# Help Me Quit (Wales)

# Tel 0800 085 2219

Text 'HMQ' to 80818

# www.helpmequit.wales

Offers information, advice and support on stopping smoking in English and Welsh.

# Stop Smoking NI (Northern Ireland)

# www.stopsmokingni.info

Has information and advice about stopping smoking. Also links to other support organisations for people in Northern Ireland who want to give up smoking.

# Counselling

# British Association for Counselling and Psychotherapy (BACP)

# Tel 0145 588 3300 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 the 'Therapist directory' page.

# UK Council for Psychotherapy (UKCP)

# Tel 0207 014 9955

# 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 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 adviceni.net

Provides advice on a variety of issues including financial, legal, housing and employment issues.

# **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

# GOV.UK

#### www.gov.uk

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

#### Law Centres Network

#### www.lawcentres.org.uk

Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

# 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 online 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 Advice Service (Northern Ireland)

Tel 0300 1233 233

# **Money Advice Scotland**

#### 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 0344 892 0902 www.nihe.gov.uk

Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

# **StepChange Debt Charity**

# Tel 0800 138 1111 www.stepchange.org

Provides free debt advice through phone, email, the website and online through live chats with advisers.

# Unbiased.co.uk

# Helpline 0800 023 6868 www.unbiased.co.uk

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

# Equipment and advice on living with a disability

# **British Red Cross**

#### Tel 0344 871 11 11 www.redcross.ora.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) 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 123 3084 www.livingmadeeasy.org.uk

Provides free, impartial advice about all types of disability equipment and mobility products.

# **Motability Scheme**

# Tel 0300 456 4566 www.motability.co.uk

The scheme enables Disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

# Scope

# Helpline 0808 800 3333

Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**.

# 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 678 1602**

#### www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

# Support for LGBTQ+ people

# **LGBT Foundation**

# Tel 0345 330 3030 Igbt.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

#### 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 0808 808 7777 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-anddiseases/cancer/scottish-cancer-registry-and-intelligence-servicescris/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 Pickering, Consultant Medical Oncologist.

With thanks to: Dr Ricky Frazer, Medical Oncologist and Clinical Lead for Acute Oncology Assessment Unit and Immunotherapy Toxicity Team; and Dr Tom Waddell, Medical Oncologist.

Thanks also to the other healthcare professionals and 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 more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk** 

Ljungberg B, Albiges L, Bedke J et al. European Association of Urology guidelines on renal cell carcinoma. March 2023. Available from www. uroweb.org/guidelines/renal-cell-carcinoma [accessed Jun 2024].

Powles T, Albiges L, Bex A, et al. Renal cell carcinoma: ESMO Clinical Practice Guideline for diagnosis, treatment and follow-up. Annals of Oncology. 2024, May 22. Available from: www.doi.org/10.1016/j. annonc.2024.05.537 [accessed Jun 2024].

# 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, money 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

1. Share your cancer experience

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

#### 2. 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.

# 3. 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?

#### 4. Raise money

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

# 5. Give money

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

# Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

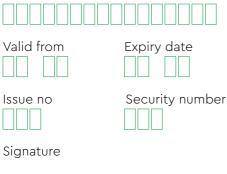
Fmail

Please accept my gift of £ (Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support OR debit my:

Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number



# Date

# Do not let the taxman keep your money

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

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

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

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

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

If you would rather donate online go to macmillan.org.uk/donate



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

This booklet is about a type of kidney cancer called renal cell cancer (RCC). It is for anyone who has been diagnosed with RCC. It may also be useful if you have another type of kidney cancer.

The booklet is about how kidney cancer may be treated. It has information about feelings, practical issues and money. There is also information for carers, family and friends.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

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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