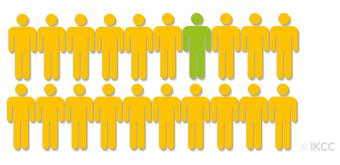
What is Kidney Cancer?

IKCC International Kidney Cancer Coalition

Kidney cancer is diagnosed in over 430,000 people worldwide every year. Kidney cancer is the 14th most common cancer in the world. Fewer than 1 in 20 people with cancer have kidney cancer, meaning that it is a less common cancer.



What is cancer?

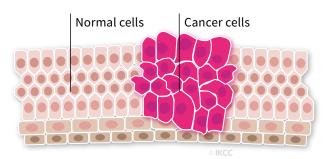
Our bodies are made up of hundreds of trillions of cells. Each tissue and organ are made of cells, which are all very different depending on where they are in the body. Our bodies are always making new cells to enable us to grow, to replace worn-out cells, or to heal damaged cells after injury. This process is controlled by the genes within the cells.

Cancer starts in normal cells. It can start in just one cell, or a small group of cells. Cells produce signals from genes that control how the cells divide. If these signals are faulty or missing the cells might grow too much.

Cancer cells develop because of changes to genes, called mutations. This causes the cancer cells to divide and grow. These changes may be caused by several factors, including diet, lifestyle, genetic factors (which are inherited from parents) and the environment.

The mutations cause the cancer to grow uncontrollably. The cancer cell grows and multiplies to form a growth or mass, called a tumour. The primary tumour is where the cancer starts.

Tumours can be either cancer (malignant) or not cancer (benign). Malignant tumours are different to normal cells. Cancer cells can spread away from the original tumour (metastasise) into nearby tissue and other areas of the body, such as the lungs, brain, and bone. Cancer cells spread through the blood or in a fluid called lymph, which is in the lymphatic system. When cancer spreads, it takes its own characteristics with it. For example, if kidney cancer spreads from the kidney to the liver, the cells in the tumour in the liver will look like kidney cancer cells and will be treated as kidney cancer cells.

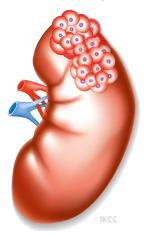


Benign tumours are not cancers. The main difference between benign and malignant tumours is that benign tumours do not spread to other parts of the body. However, benign tumours may grow and get bigger.

What is kidney cancer?

Kidney tissue is made up of very small tubes (called 'tubules') that filter and clean the blood. Kidney cancer starts in the cells in these tubes. These cells are called renal cells. Around 88% of tumours found in the kidneys are cancer (malignant). The remaining 12% of tumours found in the kidneys are not cancer (benign).

Renal cell carcinoma (RCC) is the most common form of kidney cancer and accounts for more than 80% of all cases. Not all kidney cancers are the same. There are different types of RCC. The most common type is clear cell RCC. It is important to know which type of kidney cancer you have because they are treated differently.



What is Kidney Cancer?

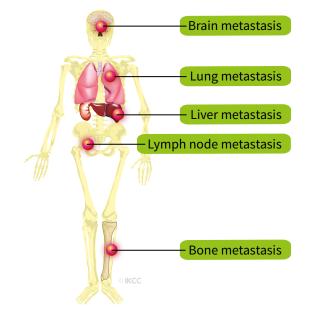


The number of people being diagnosed with kidney cancer is increasing. This maybe because of lifestyle factors and improvements in scans and better diagnosis of kidney cancer.

The symptoms of RCC are often like those caused by urinary tract infections or kidney stones. The most common symptom is blood in the urine (haematuria), which may appear suddenly and may come and go. Other common symptoms are a lump or pain in the tummy or on one side of your back. Some people also have a raised temperature, night sweats, extreme tiredness, and unexplained weight loss. Some people do not show any of these symptoms, while others may have many.

Often kidney cancer in its early stages has no signs or symptoms. In these cases, kidney cancer is found by accident on a scan carried out for other reasons or to investigate symptoms, such as high blood pressure, weight loss, high temperature, or abnormal blood tests.

About a third of people don't find out they have kidney cancer until their cancer has already spread (metastatic disease) and they have symptoms such as shortness of breath, coughing up blood, bone pain, or bone fracture. RCC most commonly spreads to the lymph nodes, lungs, bone and brain.



Good to know!

Cancer

A term for diseases in which an uncontrolled growth of abnormal cells happens which can invade and destroy nearby healthy tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems

Kidney

One of a pair of organs located below your ribs, one on either side of your spine. Kidneys remove waste from the blood (as urine), produce erythropoietin (a substance that stimulates red blood cell production), and help to regulate blood pressure.

Renal Cell Carcinoma

The most common kind of kidney cancer. It grows in the small tubes of the kidneys. Most cases are clear cell renal cell carcinoma.

Metastasis

The spread of cancer from its original (primary) site to other parts of the body. A tumour formed by cells that have spread is called a "metastatic tumour" or a "metastasis." The metastatic tumour contains cells that are like those in the original (primary) tumour. The plural form of metastasis is metastases.



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The International Kidney Cancer Coalition (IKCC) is an independent international network of patient organisations that focus exclusively, or include a specific focus, on kidney cancer. It is legally incorporated as a Foundation in the Netherlands. www.ikcc.org info@ikcc.org

What Causes Kidney Cancer?

IKCC International Kidney Cancer Coalition

Cancer cells develop because of changes to the genes in your body, called mutations. This causes the cancer cells to divide and grow. The mutations that cause cancer accumulate as we get older. Like most cancers, kidney cancer is more common in people over the age of 55 and is rare in children. Mutations may be caused by several factors, including diet, lifestyle, genetic factors (which are inherited from parents) and the environment. These are called risk factors because they increase the risk of you getting kidney cancer:

What are the risk factors for kidney cancer?

- **Increasing age:** The risk increases in people over 40 and the highest numbers of kidney cancer cases are found in those aged 85-89.
- Weight: People who are overweight (BMI 25-30) increase their risk of developing kidney cancer by about one third. If a person is obese (BMI over 30) their risk of kidney cancer is double that of a person who is a healthy weight (BMI less than 25). Around 24% of all kidney cancers result from being overweight or obese. (BMI=body mass index)
- **Cigarette smoking** can double the risk for some people and is found to be the cause of around 13% of kidney cancers. The higher the number of cigarettes smoked per day the greater the risk. It is thought that chemicals from tobacco in the blood stream damage the kidney tubules before being filtered out of the body in the urine.
- **Gender:** Men who already have certain health conditions e.g., high blood pressure (hypertension) or advanced kidney disease (especially for those on long term dialysis) are more at risk of developing kidney cancer.
- Workplace exposure to some chemicals, materials, or industrial processes e.g., cadmium, lead, asbestos, trichloroethylene, blast furnaces or coke-ovens in the steel and coal industries.

- **Certain medical conditions** such as kidney disease, kidney stones, high blood pressure and diabetes can increase your risk of developing kidney cancer.
- **Pain-relief medication** such as paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs), e.g., ibuprofen, may increase your risk of kidney cancer compared to people who have never or rarely used these medications.
- A defect of your kidney that you are born with e.g., horseshoe kidney when both kidneys are fused at one pole.
- A disorder of the kidney that is passed down in your family through your genes e.g., polycystic kidney disease is a disorder in which multiple cysts grow usually in both kidneys.
- Inherited conditions that are passed down in your family through your genes are a risk factor for some renal cancers, e.g., von Hippel-Lindau syndrome, Birt-Hogg-Dube syndrome, familial clear cell carcinoma, tuberous sclerosis, hereditary papillary renal cell carcinoma (RCC). These are called hereditary kidney cancer or genetic kidney cancer.



What Causes Kidney Cancer?



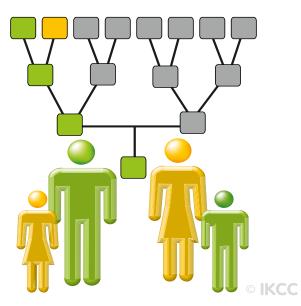
Is my family at risk of developing kidney cancer?

People who have family members with kidney cancer, especially a sibling, are at increased risk. This can be due to genes that are passed down from a parent to their child. Only about 2-4% of kidney cancer is inherited.

Signs that your kidney cancer might be hereditary include:

- Other members of your family have had kidney cancer.
- You had your first kidney tumour before you were 50 years old.
- You have more than one tumour in your kidney.
- You have tumours in both kidneys.
- You have a rarer form of kidney cancer (a non-clear cell renal cell carcinoma).

If there is a history of kidney cancer in your family, it is important that you tell your doctor so you can be tested. If the test shows that you do have a hereditary type of kidney cancer, other members of your family can be tested so that any sign of cancer could be treated early when it is most curable.





Risk factor

Something that increases your chance of developing a disease or condition.

Genetic factor

A gene that is inherited from your parents and that increases your risk of developing a hereditary disease or condition.

Gene

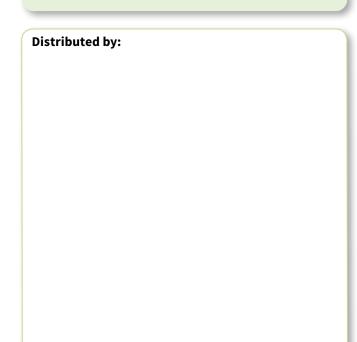
The functional and physical unit of heredity passed from parent to offspring. Genes are pieces of DNA, and most genes contain the information for making a specific protein.

Hereditary

Transmitted from a parent to child by information contained in the genes.

BMI

BMI or Body Mass Index is a measure that uses your height and weight to work out if your weight is healthy.





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Kidney Cancer Diagnosis



Most kidney cancers do not cause symptoms. Currently, there are no screening tests for kidney cancer. Doctors use their clinical experience, scans, and other tests to diagnose kidney cancer. Your doctor may use different tests depending on which signs and symptoms you have.

If you notice a change in your body that isn't normal for you, or if you have any of the signs and symptoms of kidney cancer, you should make an appointment to see your family doctor. Some of the more common signs and symptoms of kidney cancer are:

• Blood in your urine (haematuria) or a change in colour to dark brown, red, or pink.



- Pain in your lower back, stomach or side which is not linked to an injury.
- Unexplained weight loss.
- Newly developed high blood pressure.
- Constant tiredness.
- Persistent unexplained cough.

If you are worried about your symptoms, please don't delay seeing your doctor. These symptoms might not be cancer, but the earlier cancer is found, the easier it is to treat.

Depending on your symptoms, your doctor might do a general physical examination, listen to your heart, and arrange for you to give blood and urine samples. After your examination, your doctor might refer you to hospital for further tests.

Around half of all cases of kidney cancer are found when you are being checked for a different medical problem, such as a urine infection, liver problems or gut problems. In these cases, the tests detailed below will be followed.

The most common tests for kidney cancer

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Laboratory tests

Your blood and urine samples will be sent to the laboratory to check your general health and whether your liver and kidneys are working properly.

CT scan

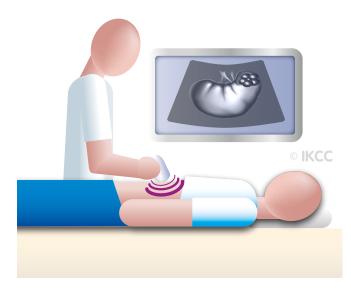
A computerised tomography (CT) scan is a special type of x-ray to take pictures of the inside of your body. If you have a tumour, it can be used to check the size of the tumour and whether it has spread to other parts of your body. This test is carried out by a radiologist.

MRI scan

Like a CT scan, a magnetic resonance imaging (MRI) scan takes picture of the inside of your body but uses a magnet instead of x-rays. If you have a tumour, an MRI scan is used to check the size of the tumour, and whether it has spread to other parts of the body. This test is carried out by a radiologist.

Ultrasound scan

An ultrasound scan uses a probe and sound waves to form pictures of the inside your body and to look for any abnormalities. This test is carried out by a radiologist.



Ultrasound

Kidney Cancer Diagnosis



If the doctor finds a tumour and thinks it may be kidney cancer, you might have some of the following tests to find out more about your cancer:

Bone scan

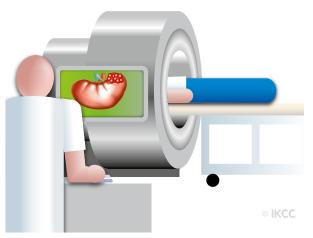
You might have a bone scan to see if there is any damage to your bones caused by the cancer spreading.

Brain scan

If you are having severe headaches, disturbed vision, or problems with your balance, you might have a CT or MRI scan to see if your cancer has spread to your brain.

Biopsy

Biopsy is the removal of a small amount of tissue using a fine needle through the skin. The tissue is examined under a microscope by a doctor called a pathologist to check for signs of cancer.



CT-Scan

What happens next?

If tests show there is a strong suspicion that you have kidney cancer, your doctor might recommend surgery to remove the tumour without you having a biopsy. Sometimes, you might have a biopsy to get more information about the tumour before you have any treatment. In about 20-30% of cases, the kidney tumour is found to be benign (not cancer).



Radiologist

A doctor who specialises in diagnosing disease using x-rays, ultrasound scans, CT scans and MRI scans.

Biopsy

The removal of a small amount of cells or tissue that is looked at under a microscope by a pathologist to check for abnormalities.

Pathologist

A doctor who identifies diseases by studying cells and tissues under a microscope.

Surgery

A procedure to remove or repair a part of the body or to find out whether disease is present.

Symptom

An indication that a person has a condition or disease. Some examples of symptoms are headache, fever, fatigue, nausea, vomiting, and pain.





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Types of Kidney Cancer

IKCC International Kidney Cancer Coalition

Kidney cancer is a type of cancer that develops in the cells of the kidney

There are several different types of kidney cancer, the most common being renal cell carcinoma (RCC). This accounts for about 85% of all kidney cancers. In RCC the cancerous cells grow in the kidney's tubules; the small tubes inside the kidney that filter blood and make urine. Most kidney cancers start growing in cells called clear cells, but they can also grow in other cells too, such as papillary cells, collecting duct cells and medullary cells.

There are also different subtypes of RCC, depending on which cells are affected or how the cells look under the microscope:

- Clear cell is the most common sub-type (65-70% of cases)
- Papillary type 1 or type 2 (15%)
- Chromophobe (5-7%)
- Collecting duct carcinoma
- Renal medullary carcinoma
- Mucinous tubular and spindle cell carcinoma
- Renal translocation carcinoma
- Unclassified RCC (the latter five are very rare and make up the remaining 5-10% of RCC tumours)
- Hereditary kidney cancer (less than 5%).



Some kidney cancers (about 12% of the total) grow at the point where the kidney joins the ureter, a thin tube that carries urine from the kidney to the bladder. This is called transitional cell carcinoma (TCC). TCC is very similar to bladder cancer and the treatments for this type of cancer are very different to the treatments for RCC.

Less than 1% of kidney cancers are renal sarcomas, which originate in the connective tissues of the kidney.

Very rarely a tumour, called a metastasis, is found in the kidney that has spread from a primary tumour elsewhere in the body. In these cases, the tumour is not kidney cancer and will be treated differently.

Sometimes benign (not cancerous) tumours may grow in the kidney. These are called kidney cysts, renal oncocytomas, or angiomyolipomas (AML) and make up about 5% of all kidney tumours.

There are some significant differences in treatment for the various types of kidney cancer. It is, therefore, important to know precisely what kind of kidney cancer has been diagnosed so you receive the right treatment. However, most patients have the clear cell RCC.

What is sarcomatoid kidney cancer?

Some kidney cancers are diagnosed as sarcomatoid kidney cancer. Sarcomatoid is a name given to a particular type of cell and can affect all the different subtypes of kidney cancer. Between 1 and 15% of kidney cancers have sarcomatoid cells. Sarcomatoid kidney cancers can be more aggressive and grow more quickly than other types of kidney cancer. They are more likely to spread to other parts of the body.

Types of hereditary kidney cancer

There are several different types of hereditary kidney cancer, which are passed down in the genes from a parent to their child. Research is ongoing to find out more information about the genes that cause kidney cancer. These genes could be used as biomarkers to predict who will get kidney cancer in the future.

- Von Hippel–Lindau (VHL): This is caused by a mutation in a gene called the VHL gene and usually causes clear-cell RCC.
- Hereditary leiomyomatosis and renal cell carcinoma (HLRCC): This is caused by a mutation in the FH gene and usually causes type 2 papillary RCC.

Types of Kidney Cancer



- Hereditary papillary renal cell carcinoma (HPRCC): This is caused by a mutation in the MET gene and usually causes type 1 papillary RCC.
- **Birt-Hogg-Dubé (BHD):** This is caused by a mutation in the FLCN gene and usually causes chromophobe RCC or a benign tumour called an oncocytoma.
- Renal cell carcinoma with hereditary paraganglioma and phaeochromocytoma: This is caused by mutations in the SDHB or SDHD gene.
- Chromosome 3 translocation familial renal cell carcinoma: This is caused when a part of a chromosome (a string of DNA containing several genes) breaks off and attaches to different chromosome.
- Tuberous sclerosis complex (TSC): This is caused by a mutation in the TSC1 or TSC2 gene and usually causes a tumour called an angiomyolipoma. These tumours are benign, but they have many blood vessels, which can burst and lead to life-threatening internal bleeding if not treated.

Kidney cancer in children

In rare cases, children can get kidney cancer. Usually, they develop a different type of kidney cancer than adults, called Wilms' tumour (or nephroblastoma), which is usually diagnosed in children aged 2-5. However, there have been very rare cases of children with RCC or adults with Wilms' tumour.

Good to know!

Tubules

The small tubes inside the kidney that filter blood and make urine.

Sarcomatoid

Sarcomatoid means that the cells of the cancer look like sarcoma cells. Sarcoma is cancer of the body's supporting tissues, such as muscle, nerves, fat, blood vessels and fibrous tissues.

Nephroblastoma

Also called Wilms' tumour. A rare kidney cancer that affects children.

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