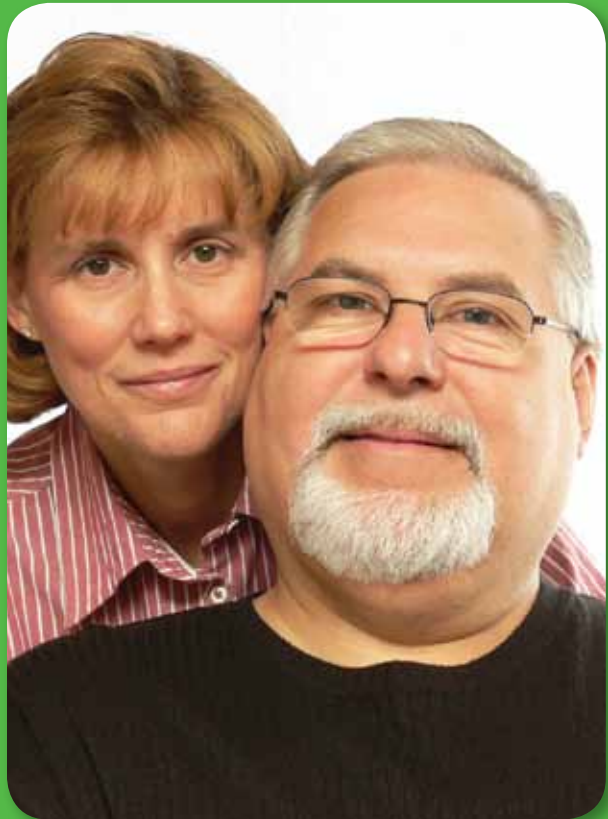


# Understanding Kidney Cancer



## An information guide

From James Whale Fund for Kidney Cancer 2.1 edition - February 2011



Many people suffer from kidney cancer and continue to lead fulfilling lives. We hope this booklet will help you to do the same.

# CONTENTS

- 2 *Kidney cancer*
- 4 *Getting a diagnosis*
  - The symptoms of kidney cancer**
  - How doctors diagnose kidney cancer**
  - What are my chances?**
- 10 *Having treatment*
  - Staging and grading kidney cancers**
  - Discussing treatment options**
  - Surgery**
  - Biological therapies**
  - Other treatments**
- 24 *Living with kidney cancer*
  - Feelings**
  - Day-to-day living**
  - Palliative care**
  - Money matters**
  - Support**
  - Self-help**
- 28 *Where to find more information*
- 30 *Glossary*
- 36 *Notes*

Words in **bold** are explained in the glossary

The James Whale Fund for Kidney Cancer does not supply medical advice. The information provided in this booklet is for educational purposes only and is not a substitute for professional care. It should not be used for diagnosing or treating health problems. If you have, or suspect you may have a health problem you should contact your doctor.

You can visit the Kidney Cancer Support Network forum at [www.kidneycancersupportnetwork.co.uk](http://www.kidneycancersupportnetwork.co.uk) and the James Whale Fund for Kidney Cancer at [www.jameswhalefund.org](http://www.jameswhalefund.org). Call the **Kidney Cancer Careline** on **0330 111 2 333**

By the time you read this, you (or someone close to you) will have probably seen a doctor and had some tests.

You may have sought help or advice because you were experiencing one of the symptoms of kidney cancer.

Or you may have been diagnosed with kidney cancer following a scan for something completely different.

This booklet will help you understand what is likely to happen next.

- It will tell you about the investigations the doctors might carry out.
- It will explain the different treatments available as well as the possible side-effects of each.
- It will suggest some questions you might like to ask your doctors so that you can decide on the course of action that's right for you.
- And it will tell you where you can get further information and support.

## Kidney Cancer

Every year in the UK, more than 8,000 people learn that they have kidney cancer. The incidence of kidney cancer is slowly increasing in the UK, possibly due to an increase in the number of cases detected when a patient has a scan for an unrelated condition. This is because scans are performed more frequently in hospitals and there have been huge improvements in scanning technology over the past 30 years. Kidney cancer is now the seventh most common type of cancer among men and ninth among women in the UK.

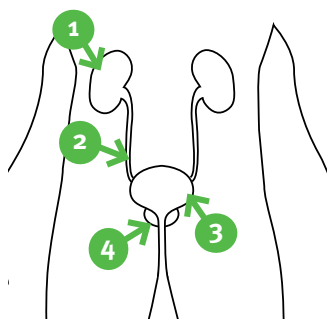
Kidney cancer more often affects older men, who usually appear healthy. It is not unusual to discover a tumour on the kidney incidentally whilst the patient is having a scan for an unrelated condition.

The risk of developing kidney cancer is highest in the 45-75 age group, and tails off in the late seventies. Other factors that can predispose people to the disease are; an unhealthy diet (obesity), smoking, genetic factors (such as a mutation in the von Hippel-Lindau gene), and gender (men are twice as likely to suffer from kidney cancer than women). Also, there is evidence to suggest that some workplace chemicals, such as asbestos, cadmium and some organic solvents, have been linked to an increased risk of developing kidney cancer, and people on long term kidney **dialysis** and people with hypertension are also at greater risk.

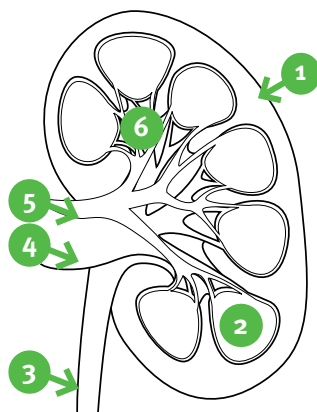
The most common early symptom is blood in the urine. If kidney cancer is diagnosed at an early stage, there is a good chance of a cure by removal of the affected kidney to prevent the spread of the disease. The more the cancer has grown and spread throughout the body, the less chance that the treatment will cure the patient completely. However, treatment can often slow the progress of the cancer.

The most common form of kidney cancer is **renal cell carcinoma** or RCC for short. About 90% of kidney cancers are RCCs. There are several different sub-types of RCC. The most common of these is **clear cell**, which account for 75-80% of RCCs. This booklet concentrates on RCC, although some of the information should be helpful to any kidney cancer patient.

More information about other types of kidney cancer, including **Wilms' tumour**, which affects young children, and hereditary kidney cancer syndromes, such as **von Hippel-Lindau** and **Birt-Hogg-Dubé**, can be obtained from our website [www.jameswhalefund.org](http://www.jameswhalefund.org) or from [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk), a Cancer Research UK website (see pages 28 and 29).



- 1 Kidney
- 2 Ureter
- 3 Bladder
- 4 Urethra



- 1 Cortex
- 2 Medulla
- 3 Ureter
- 4 Renal vein
- 5 Renal artery
- 6 Calyces

## Getting a diagnosis

### The symptoms of kidney cancer

The most common symptom is blood in the urine. Doctors call this **haematuria**. It may come and go and not every kidney cancer sufferer will have haematuria. Sometimes you won't be able to see it, but it can still be detected by a urine test. Most people with blood in their urine do not have kidney cancer. It can be a sign of an infection, kidney stones, prostate problems or bladder cancer. However, it should always be investigated to find out what has caused it. The sooner kidney cancer is detected, the easier it is to treat.

Most kidney cancers are too small to feel but if you feel a lump or mass in the area of your kidneys you should tell your doctor straight away. You should also see your doctor about any persistent low back pain or loin pain.

In the early stages of kidney cancer there may be no obvious symptoms. Many kidney cancers are found simply by chance when someone is being given a scan for another reason. More than half of adult kidney **tumours** are detected when using an **ultrasound scan** to investigate symptoms, such as high blood pressure, muscle wasting and weight loss, high temperature or fever, disorders affecting the nerves and muscles, inflammation, anaemia, abnormal liver function tests, high levels of calcium in the blood (**hypercalcaemia**), and thickening of the blood (**polycythaemia**).

Sometimes abnormal red blood cell counts and high blood pressure, or **hypertension**, can be symptoms of kidney cancer. Some patients experience a condition called **polycythaemia**, or thickening of the blood, which can be a symptom of kidney cancer. Symptoms of polycythaemia are a bad headache and redness of the skin.

In about a third of patients, the kidney cancer will have already spread to other organs, such as the lungs, liver, brain and bones. These patients may experience symptoms of advanced kidney cancer, such as a persistent cough, coughing-up blood, abnormal liver function tests, headaches and visual disturbances, or bone pain. You must see your doctor if you have any of these symptoms.

There are other symptoms which can be more general and can also be caused by many other conditions (see box).

### Typical symptoms

- ▶ Blood in the urine
- ▶ Tiredness
- ▶ Weight loss and/or loss of appetite
- ▶ Running a persistent temperature and sweating heavily, especially at night
- ▶ Persistent low back pain or loin pain
- ▶ Abnormal red blood cell counts
- ▶ High blood pressure
- ▶ Thickening of the blood (polycythaemia)

### How doctors diagnose kidney cancer

Currently, there are no effective screening programmes for kidney cancer in the UK. Doctors use their clinical experience (clinical suspicion) and scans to identify kidney cancer.

### At your GP surgery

Some initial tests will probably be carried out by your family doctor. He or she will ask about your general health, examine you and ask for a urine sample. This will be analysed to see if it contains blood. You may also be asked for a blood sample. This will be tested to see how well your kidneys are working. He or she may also perform a **physical examination** to check for any lumps or swelling; however, small tumours are difficult to detect on a physical examination because the kidneys are deep inside the body.

### Questions you may want to ask your doctor

- ? What tests are you going to do?
- ? What are you looking for?
- ? What will happen and how long will it take?
- ? Will it be painful or uncomfortable?
- ? Will there be any after-effects?
- ? Can I bring someone with me?
- ? How long will the results take?
- ? Who will give me the test results?
- ? Will they show if I have kidney cancer?
- ? Will they show if the cancer has spread?

Your GP may then refer you to a hospital specialist for further tests, especially if you have blood in your urine. There are special referral guidelines for GPs to help them decide who needs to be referred to a specialist urgently.

### **At hospital**

The hospital specialist, usually a **urologist**, will want to know about your medical history and symptoms. If anyone else in the family has had kidney cancer you should mention this. You will have more blood and urine tests, such as a **full blood count** (FBC) and **urea and electrolytes** (U&Es), to calculate the risks that you face and to test the function of your kidneys. If you want to know the results of your blood tests, please ask your doctor to explain them.

Your doctor will also want to look at your kidneys. Usually, the first test he or she will do is an **ultrasound scan**, which is a real-time, moving test used to detect and differentiate between tumours and **cysts** on the kidney. This is a painless procedure which is done in the hospital scanning department and only takes a few minutes to perform. You lie down and gel is spread on your abdomen. A small probe which produces sound waves is rubbed over the area. The sound wave echoes are detected by the probe and turned into a picture of the organs and structures inside your body by a computer.

Your doctor might arrange for a special X-ray examination of your urinary system, called an **intravenous urogram** (IVU) or **intravenous pyelogram** (IVP). This test helps your doctor to detect obstructions or abnormalities in your urinary system and assess the function of your kidneys, ureters and bladder. It is done in the hospital X-ray department and takes about an hour. A special dye, called a **contrast agent**, is either injected into a vein in your arm, or given to you in a drink, and a doctor watches on a screen as it travels through the kidneys. The dye may make you feel hot and flushed for a little while, but the feeling gradually disappears. You should be able to go home as soon as the test is over.

If you have blood in your urine, your doctor might want to carry out a **cystoscopy** to check inside your bladder. The procedure can be done under local or general anaesthetic. A fine, flexible tube with a light in the end (called a **cystoscope**) is passed up your urethra and into your bladder where it acts like a telescope allowing the doctor to see inside your bladder.



If the initial investigations confirm you have kidney cancer, you will need more tests to help doctors see if it has spread and how best to treat it. However, some of the following tests may also be used when your doctor is still trying to determine whether you have kidney cancer or not:

### Typical tests

- i CT scan
- i Biopsy
- i MRI
- i Bone scan
- i Chest X-ray
- i Ultrasound scan

### CT scan

**Computerised tomography** (CT) is a special type of X-ray examination and is conducted in the X-ray department of the hospital. A CT scan is used to check the size of the tumour and whether it has spread to other organs, such as the lungs and the other kidney.

The CT scanning machine takes a series of X-ray pictures of your body from different angles. These images are put together by a computer to give a detailed image of the inside of your body. You will need a full bladder for this examination, so you will not be able to go to the toilet before hand. The machine is shaped rather like a ring doughnut. You lie on a couch which slides backwards and forwards through the hole. The radiographer cannot stay in the room with you during the scanning but will be able to see you on a tv screen and talk to you through an intercom. You may be given an injection of a special dye, or **contrast agent**, into a vein to help blood vessels show up more clearly. A CT scan is painless but takes longer than an X-ray. The length of the whole procedure depends on how many pictures are taken, but expect to be on the couch for about 30 minutes. Some people feel a little claustrophobic during a scan. If you think you might, tell the radiographers before the day of your appointment.

CT is currently the gold-standard for looking at kidney tumours. However, more specific scanning techniques are now starting to be used in some hospitals. For example, **positron emission tomography** (PET) using mildly radioactive form of glucose is used to find malignant tumours. Malignant cells take up more glucose than normal cells and therefore 'light up' on the PET scan. PET using a radioactive isotope of the CA9 protein, which is specific to cancerous kidney cells, can also be used to identify malignant tumours in the kidney.

### **Biopsy**

Doctors can usually make a confident diagnosis from a CT scan alone. Occasionally a **biopsy** will also be carried out. A thin needle is put through the skin and muscle into the kidney to remove a small sample of tissue. This is then examined under a microscope to check for signs of cancer.

Biopsies are usually taken during surgery to remove the affected kidney and are also used to determine the type of kidney cancer a patient has, for example, clear cell or papillary.

### **MRI scan**

**Magnetic resonance imaging** (MRI) is a type of scan that uses magnetism instead of X-rays to construct a detail picture of the inside of your body. MRI is used to check the size and extent of a tumour, and to determine whether or not the cancer has spread to other organs of the body. You may be given an injection of special dye or contrast agent into a vein to help the tumours show up more clearly on the MRI scan picture.

Similar to the CT machine, the MRI machine is shaped like a long tube and you lie on a couch which slides backwards and forwards through the hole. The radiographer watches you on a tv screen and can talk to you through an intercom. During the test you have to lie very still on the couch inside the tube for about 30 minutes. It is painless but very noisy and can make people feel a little claustrophobic. If you think you might feel claustrophobic during your scan, please tell the radiographer before your appointment. You should be given earplugs or headphones through which you can listen to music and will be able to hear the radiographer.

### Bone scan

You might be asked to have a **bone scan** to see whether the cancer has spread to your bones. If so, you will be injected with a mildly radioactive material and then asked to wait for a couple of hours while it travels through the blood and collects in the bones. Areas where there is damage to the bone will show up as ‘hot spots’. These aren’t necessarily the result of cancer. If you have arthritis, for instance, this will show up on the scan.

### Chest X-ray

A chest X-ray may be carried out to check your general health and make sure that you are fit enough to have certain treatments or surgery. It will also be used to rule out cancer spread to the lungs or chest bones.

You will be asked to go back to hospital for the results of your tests. This may take a little while and you will probably feel worried and upset during this time. Is there anyone you can share your feelings with? Is there a **clinical nurse specialist** you can talk to? It might be helpful to contact a support group and talk to someone who has been in your shoes. There are some useful numbers on pages 28 and 29.

### What are my chances?

Being told you have kidney cancer is always a shock. People react in different ways. Some want to find out as much as they can about their treatment and their long-term prospects. Others don’t want to think about the future, preferring to take each day as it comes without worrying about what may or may not lie ahead.

As doctors know only too well, it can be very difficult to predict what will happen because every patient is an individual. Of course, **the earlier your cancer is detected and the sooner treatment begins, the better your chances of long-term survival.** Even if your cancer has spread, making it more difficult to treat, it is possible for the symptoms to be kept well under control for years. And in some rare cases patients may go into **remission** for no apparent reason.

There are statistics about average survival rates for people diagnosed with different stages of kidney cancer. You can look at these on [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk) if you choose to. If you do, bear in mind that these are averages and will not tell you how well you will do. Some patients, originally warned that their prospects of survival were poor, have lived for much longer and had a much better quality of life than expected.

## Having treatment

Before your doctors can discuss treatment options with you they need to know how far your cancer has progressed.

### Staging and grading kidney cancers

**Staging** is used to describe how big a cancer is and how far it has already spread. The **TNM system** is a common system used for staging tumours;

<b>T (tumour)</b>	plus a number indicates the size of the <b>primary tumour</b> and how far it has grown locally. The number refers to the stages described below.
<b>N (nodes)</b>	plus a number indicates that the cancer has spread to nearby <b>lymph nodes</b> . The number refers to the number of affected lymph nodes.
<b>M (metastases)</b>	plus a number refers to places elsewhere in the body where the cancer has spread. The number refers to the number of metastases.

Your doctor will combine these figures to give an overall staging, e.g. T<sub>2</sub> N<sub>0</sub> M<sub>0</sub>, which means the cancer is bigger than 7cm but still confined to the kidney, there is no involvement of lymph nodes and there are no **metastases**.

Another staging classification which is sometimes used for kidney cancer is a number system; the cancer is simply said to be stage 1, 2, 3 or 4 (or stage I, II, III, or IV). Again, the stages reflect how large the primary tumour has become, and whether the cancer has spread to lymph nodes or other areas of the body. A stage 4 tumour is often referred to as an **advanced cancer**.

The number system used for kidney cancer is as follows;

- ! Stage 1** The cancer is confined to the kidney and is less than 7cm in size
- ! Stage 2** The cancer is bigger than 7cm but still confined to the kidney
- ! Stage 3** The cancer has started to spread outside the kidney
- ! Stage 4** The tumour has either spread to nearby organs or to other parts of the body further away.

Finding the stage of a cancer helps doctors to advise on what is the best treatment and gives them a reasonable indication of the outlook (**prognosis**). It also describes the cancer in a standard language which is useful when doctors discuss patients, and when patients are involved in clinical trials. When discussing your treatment options, your doctor will also take into account how well you are overall.

Doctors **grade** cancers to indicate how quickly or slowly a cancer is likely to grow and spread. Cells from a sample of the cancer (a biopsy) are looked at under the microscope or tested in other ways. By looking at certain features of the cells the cancer can be graded as low, intermediate or high grade;

- ! Grade 1 or low grade** Cells are usually slow-growing, look quite similar to normal cells, tend to be less aggressive and are less likely to spread.
- ! Grade 2 or intermediate** Cells grow more quickly, look abnormal, are moderately aggressive and could spread.
- ! Grade 3 or high grade** Cells are likely to grow more quickly, look very abnormal, tend to be more aggressive and are more likely to spread.
- ! Grade 4 or high grade** Cells look very abnormal, grow very quickly, are extremely aggressive and are very likely to spread.

## Discussing treatment options

Ideally you will be treated in a cancer unit by a team of specialists or **multi-disciplinary team** (MDT). They will discuss your treatment with you. The team will include a urologist who specialises in surgery and, if your cancer has spread, an oncologist who specialises in other ways of treating cancer. Preferably, both will have experience of treating kidney cancer.

### Medical specialists

- ✚ Clinical Nurse Specialist
- ✚ Dietician
- ✚ Physiotherapist
- ✚ Occupational Therapist
- ✚ Psychologist
- ✚ Oncologist
- ✚ Urologist

Other members of the team may include a **clinical nurse specialist**, a dietician, a physiotherapist, an occupational therapist and a psychologist or counsellor.

Your doctors will tell you which treatment they think would be best for you. Sometimes they may offer you a choice of treatments. In any case, you should be sure you have been given enough information, and understood it, before you give permission for the treatment to start. Don't be embarrassed about asking people to explain things again. And remember to ask about any aspects that are worrying you.

You should be told:

- ✔ What type of treatment the doctors are advising
- ✔ How and when this would be carried out
- ✔ The advantages and disadvantages of this type of treatment
- ✔ Any possible other treatments that might be available
- ✔ Any significant risks or side effects of the treatment.

It may be useful to write down a list of questions to take with you to the appointment. It is also a good idea to have a relative or friend with you when you are discussing your treatment options. They will be able to take notes or help you remember what was said. If you feel you can't make a decision straightaway, ask for more time to decide.

You may want a second opinion, especially if you feel your doctor does not have enough experience in treating kidney cancer or if you are told little treatment is available. Most doctors will be willing to refer you to another specialist but it may take a little while to organise. As this may delay the start of your treatment you need to feel sure it will be worthwhile.

If the treatment you are being offered aims to cure your cancer, you may find the decision to go ahead relatively easy. But if, instead, the aim of the treatment is to control the cancer for a period of time it may be more difficult to decide.

You might want to think about your **quality of life** while you are having treatment. Will you have to travel back and forth to hospital? What are the side-effects of treatment? Can the side-effects be treated?

As well as talking things over with the people who mean most to you, you may find it helpful to talk to a counsellor or a specialist nurse. If you choose not to have treatment you can still be given help to control any symptoms you have. This is called **palliative care** and can be offered to help patients through their entire cancer journey. Palliative care also gives people support with social, spiritual and psychological issues. Carers and family may also be offered emotional and spiritual support. See page 25 for more on palliative care.

## Surgery

Surgery to remove part or all of the kidney (**nephrectomy**) is usually the first thing doctors consider and it **can be a cure if the cancer is at an early stage**. Even some more advanced cancers can be cured if all the cancer can be removed. However, removing a kidney is a major operation so you need to be fit enough to cope and recover afterwards. That's why this treatment may not be possible for everyone. Surgery can also be used to removed metastases in some cases of advanced kidney cancer.

Removing part of a kidney is called a **partial nephrectomy**. It means that some working kidney is left behind. Specialist surgeons now treat many small tumours this way if possible.

During a **radical nephrectomy** the whole kidney and the surrounding fatty tissue, the adrenal gland, and nearby lymph nodes are usually removed, although the extent of a radical nephrectomy can vary between patients. You can live perfectly well with just one working kidney, but if both kidneys are removed because of **bilateral renal cell carcinoma**, or because they are not working you will need dialysis for the rest of your life.

The surgeon usually makes a cut between the lower ribs on the side of the tumour. This is called open surgery. Sometimes it is possible to use keyhole surgery or **laparoscopic nephrectomy** instead, for which you would need a referral to a specialist urological surgeon with particular experience in laparoscopic kidney surgery. Laparoscopic nephrectomy can be carried out for patients for whom open surgery is not an option, for example patients with high blood pressure. The operation is carried out using several small incisions or cuts rather than one large incision. There may be some advantages to having keyhole surgery. For example, you may experience less pain after the operation, need a shorter stay in hospital and have smaller scars. However, keyhole surgery, like any operation, has some risks, so you should discuss the options with your specialist before surgery.



After the operation you will be given an intravenous drip of fluid and salts until you can eat and drink normally. Tubes will drain excess fluid from your wound to assist healing. These will be taken out before you go home. You will probably have a **catheter** fitted to drain your urine into a bag. This is usually taken out after a day or two.

Most people go home between four to ten days after their operation depending on the type of surgery they had. The time it takes for you to feel fit enough to get back to leading a normal active life will vary. It may help to talk to your doctor or clinical nurse specialist about this.

### **Follow-up after surgery**

There are no guidelines for the method and timing of follow-up examinations after surgery. You will be follow-up for signs of **recurrence** of the cancer or spread of the cancer to other parts of the body. The frequency of follow-up visits and the tests that you receive during these visits will depend upon whether you experience any complications as a result of your operation, the function of your remaining kidney, and the risk of recurrence of the cancer or spread to other parts of the body. In general, you should have follow-up visits at 6 months and 1 year after your surgery, and then annually for at least 5 years. Patients at a low risk of recurrence or cancer spread should have an ultrasound scan or chest X-ray, and blood tests to check kidney function at each visit. Patients at an intermediate or high risk of recurrence or spread should have a CT scan and blood tests at each visit. Patients at an intermediate or high risk of recurrence or spread, or those with complications after their operation may be seen more frequently.

## New surgical methods

Doctors have been researching less invasive ways of removing kidney tumours. **Cryotherapy** kills the cancer cells by freezing the tumour while **radio-frequency ablation (RFA)** uses heat from an electric probe. **High intensity focused ultrasound (HIFU)** directs strong beams of sound at the tumour which kills cancer cells. The main advantage of these techniques is that they can be done using probes through the skin so you don't have to have open surgery. These approaches maybe useful if your tumour is small, or when open or keyhole surgery to remove your kidney is not an option. However, these techniques are not widely used and their success is yet to be proven.

If your surgeon is confident that all your cancer has been removed during surgery, you won't need any further treatment. However, if there is concern that some cancer cells were left behind after surgery, you may need to have treatment with a drug called a **biological therapy** or a course of **radiotherapy**.

## Biological therapies

Biological therapies are drugs made from natural substances found in the body which are used to kill cancer cells or stop them from growing. Biological therapies are used to try to shrink or control advanced kidney cancer and help people to live longer. You may be given biological therapies for kidney cancer that has already spread or is at high risk of coming back after surgery. Biological therapies given to patients to try to stop kidney cancer from coming back or **recurring** after surgery is called **adjuvant therapy**.

Some people with advanced kidney cancer respond very well to biological therapies, and the treatment can control their cancer for a number of months or even years. There is a great deal of research going on to try to find out why certain patients do so well and which is the best combination of drugs to give to patients with advanced kidney cancer. You can get more information about clinical trials from the James Whale Fund for Kidney Cancer and Cancer Research UK (see pages 28 and 29).

Several different types of biological therapy are used for kidney cancer, including **immunotherapy**, **protein kinase inhibitors**, **monoclonal antibodies** and **vaccines**.

## Immunotherapy

This approach stimulates the body's own immune system to attack the cancer cells. It uses man-made copies of substances found naturally in the body. These include interferon-alpha-2a and interleukin-2. They are used to shrink the cancer and reduce the symptoms it is causing.

**Interferon alpha-2a** (Roferon-A® or IntronA®) works by helping to stop the cancer cells from growing, and by boosting the immune system to attack the cancer. It may also restrict the blood supply to the cancer cells. Interferon is usually given three times a week by an injection under the skin using a very fine needle. You or a relative can be taught to do this at home using a pen-injection device or a pre-filled syringe.

You can arrange for a nurse to visit you at home to help you manage the first few times and give advice on managing any side-effects. These can be similar to flu symptoms: chills, fever, headaches, and aches and pains in your back, joints and muscles. Taking paracetamol half an hour before an injection and then every six hours until the symptoms subside often helps. Other side-effects include nausea, loss of appetite and tiredness. The side-effects tend to lessen as the treatment continues

**Interleukin-2** or **aldesleukin** (Proleukin®) stimulates white blood cells called T-lymphocytes to attack the cancer. It can be given as an injection under the skin or by a drip into a vein. The side-effects are similar to those of interferon but likely to be worse and vary depending on the dose.

The most common side-effects include chills, fever, headache, aches and pains, nausea and vomiting and loss of appetite. The therapy may also cause changes to the pattern of your heartbeat, fluid on the heart or lungs, or problems such as depression or confusion. This is why it is usually only given to patients in specialist cancer centres where doctors and nurses can help them manage the side-effects.

You might be offered one of these immunotherapies as part of a clinical trial. Researchers are investigating the use of immunotherapies after surgery to lower the risk of the cancer coming back (adjuvant therapy). Clinical trials are also investigating the use of immunotherapy in combination with chemotherapy (**combination therapy**) for the treatment of advanced kidney cancer. More information about clinical trials can be found at [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk), a Cancer Research UK website, or from [www.jameswhalefund.org](http://www.jameswhalefund.org) (see page 28 and 29).

### **Protein Kinase Inhibitors**

Sunitinib comes as a capsule, which is swallowed. You usually take one 50mg capsule a day for four weeks, followed by two weeks off. Sorafenib is usually taken as two 200mg tablets twice a day, and pazopanib as one tablet once a day for as long as the treatment is helping.

Tyrosine kinase inhibitors, such as **sunitinib (Sutent®)**, **sorafenib (Nexavar®)** and **pazopanib (Votrient®)**, block the effects of the tyrosine kinases involved in new blood vessel growth that is essential for cancer cells to divide and grow. These treatments starve the tumour by stopping the development of a new blood supply (**angiogenesis**). Doctors call treatments that interfere with the development of a blood supply **anti-angiogenic agents**.

Sunitinib comes as a capsule, which is swallowed. You usually take one 50mg capsule a day for four weeks, followed by two weeks off. Sorafenib is usually taken as two 200mg tablets twice a day, and pazopanib as one tablet once a day for as long as the treatment is helping.

The most common side-effects included fatigue, stomach upsets from diarrhoea to nausea and vomiting, skin discoloration, red and blistered hands and feet, sore mouth, an increase in blood pressure, and loss of taste and appetite. Many of these side effects can be controlled with medication and they do not affect everyone. You may only have one or two side effects. A side effect may get worse through your course of treatment, or more side effects may develop as the course goes on. Your specialist nurse or doctor should give you a contact number for you to ring if you are worried about side effects or have any questions. You need to tell your specialist nurse

or doctor about your side effects so they can help you manage them. You also need to tell your doctor about any other medicines you are taking, including vitamins, herbal supplements and other over-the-counter remedies.

In the UK, both sunitinib and pazopanib are used as first-line treatment for advanced RCC. Sorafenib is recommended for use after interferon or interleukin has failed to help or if patients cannot tolerate these treatments i.e. as a second-line treatment.

Sunitinib, sorafenib and pazopanib have all been licensed for the treatment of people with advanced kidney cancer and the National Institute for Health and Clinical Excellence (NICE) have issued guidance that recommends sunitinib and pazopanib as a first-line treatment options in NHS hospitals. No second-line treatment options have been recommended by NICE, however funding for second-line treatments can be obtained through government funding schemes, such as the Cancer Drugs Fund, or you may have access to second-line treatments as part of a clinical trial.

Another group of protein kinase inhibitors, called mTOR inhibitors, such as **temsirolimus (Torisel®)** and **everolimus (Afinitor®)**, act in a similar manner to TKIs by interfering with the signalling pathway that controls tumour cell growth and angiogenesis. Temsirolimus is given as an infusion over 30-60 minutes once a week for as long as it is working. Everolimus is an oral treatment and is taken once daily. mTOR inhibitors are treatments for advanced kidney cancer that has come back during or after treatment. Side effects to mTOR inhibitors are similar to those for TKIs.

Both temsirolimus and everolimus are licensed for the treatment of advanced kidney cancer in the UK, however they have not been recommended by NICE. Funding for these treatments can be obtained through government funding schemes, such as the Cancer Drugs Fund, or you may have treatment with mTOR inhibitors as part of a clinical trial.

You can find more information about sunitinib, sorafenib, pazopanib, temsirolimus and everolimus on the **CancerHelp UK** website [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk) (see page 29)

For more information about government funding schemes, in particular the Cancer Drugs Fund, please contact the **Patient Support Team** at the James Whale Fund for Kidney Cancer on **0330 111 2 333**, visit [www.kidneycancercare.org.uk](http://www.kidneycancercare.org.uk) or email [kcc@jameswhalefund.org](mailto:kcc@jameswhalefund.org).

### Monoclonal antibodies

**Bevacizumab (Avastin®)** is a monoclonal antibody which recognises and blocks a protein in the blood called **vascular endothelial growth factor (VEGF)**. VEGF acts on cells and is part of the signalling pathway that helps cancers to grow blood vessels. All cancers need a blood supply to be able to survive and grow. Like protein kinase inhibitors, bevacizumab starves the tumour by stopping the development of a blood supply and is therefore another anti-angiogenic agent. Bevacizumab is given in conjunction with interferon-alpha to boost the effect of interferon-alpha.

Bevacizumab is administered through a drip into a vein every 2 weeks. The first dose is given over an hour and a half and if you don't have any problems, the infusion time can gradually be reduced to 30 minutes.

The most common side effects associated with bevacizumab are high blood pressure during treatment, feeling sick, constipation, diarrhoea, fatigue, pain and weakness affecting your joints, muscles, chest and abdomen, numbness or tingling in fingers and toes, slow wound healing, protein in your urine and increased risk of bleeding. Most of these side effects can be treated and they do not affect everyone. You need to tell your specialist nurse or doctor about your side effects and any other medicines you are taking.

#### Drug treatments available on the NHS

- ✓ Interferon alpha-2a (Roferon-A® or IntronA®)
- ✓ Interleukin-2 or Aldesleukin (Proleukin®)
- ✓ Sunitinib (Sutent®)
- ✓ Pazopanib (Votrient®)

#### Drug treatments licensed for use but not available on the NHS

- ✓ Sorafenib (Nexavar®)
- ✓ Bevacizumab (Avastin®)
- ✓ Everolimus (Afinitor®)
- ✓ Temsirolimus (Torisel®)

## Vaccines

Cancer vaccines are designed to stimulate the body's own immune system to fight cancer. Research is going on into vaccines that will stop or slow down advanced kidney cancer, or reduce the risk of the cancer coming back after surgery. Vaccines can be made from tumour cells or a type of white blood cell called dendritic cells. Tumour cell vaccines are made from each individual patient's kidney cancer cells, which are removed during surgery. Kidney cancer cells and dendritic cells are mixed together in a laboratory and are injected back into the patient as a vaccine. Cancer vaccines are only available in clinical trials.

## Other treatments

### Arterial embolisation

**Arterial embolisation** is a minor procedure compared to surgery in which the blood supply to the area of the kidney containing the tumour is blocked. This reduces the supply of oxygen and nutrients to the tumour, causing it to shrink thereby making it easier to control or remove surgically. Arterial embolisation is not a cure, however; if the tumour is not removed, there remains a high chance of cells breaking away from the tumour and spreading to other parts of the body. Embolisation is also sometimes used before surgery to reduce the risk of bleeding.

Arterial embolisation is done in the hospital X-ray department and you will have to stay in hospital at least overnight. You will be given something to make you sleepy and a local anaesthetic. The doctor will feed a long tube, called a catheter, into the main blood vessel in your groin using X-ray images on a screen to guide the catheter into the correct position. He/she will then inject small pieces of gelatine sponge or some plastic beads into the artery that leads to the kidney, cutting off the blood supply to the tumour.

## Radiotherapy

**Radiotherapy** uses high-energy rays to destroy cancer cells. It can be used to shrink a kidney cancer and so control symptoms. It can also be used if the cancer has spread to other areas of the body, such as the brain, lungs, liver or bone. Because kidney cancer cells are not very sensitive to radiation, radiotherapy is not used very often to treat kidney cancer patients.

Radiotherapy may be used to help control and alleviate the symptoms of advanced kidney cancer. It can be used to shrink a large tumour and relieve pressure on nearby organs and the subsequent pain and discomfort this causes. Shrinking the tumour may also relieve the pressure on nerves that may be causing pain (**neuropathic pain**).

Treatment is given in the hospital radiotherapy department and will be tailored to you. Some people have daily treatments (or **fractions**) from Monday to Friday for several weeks. Others may need only one or two treatment fractions.

Radiotherapy can be directed at the area of the body containing the tumour so as to kill most of the cancer cells and avoid as much healthy tissue as possible. The actual treatment only takes a few minutes and does not hurt. You will be able to talk to the radiographer via an intercom if you need them.

Side-effects can include fatigue, nausea and vomiting, and sore or red skin. They take a while to build up and usually persist for a while after the treatment has finished. Your doctor will be able to tell you what to expect and how to cope.

If your cancer has spread to your brain, radiotherapy can be very successful at controlling symptoms and slowing down the growth of the cancer. It can be given in a number of different ways and is usually given in combination with steroids. How it is given depends mostly on the size and number of areas of cancer spread in the brain. If there is only one area affected, it may be treated with **stereotactic radiotherapy** (also called **radiosurgery** or **gamma knife surgery**) using high doses of radiation directed at the cancer using a head frame. Only a single treatment is required. If stereotactic radiotherapy is not available, lower dose radiation is given in 10



separate fractions over 2 weeks. If the cancer is widespread, there is the possibility of the spread of cancer cells throughout the brain which are too small to detect on a scan. In this case whole brain radiotherapy is sometimes employed. This is usually given in 5 fractions over a week.

### Chemotherapy

**Chemotherapy** is the use of anti-cancer or **cytotoxic** drugs to destroy cancer cells. The drugs may be given as tablets or, more likely, by injection into a vein. Chemotherapy isn't generally used for kidney cancer because the biological therapies are more effective. However, you may be offered chemotherapy as part of a clinical trial of new drugs or in combination with biological therapy. Different types of kidney cancer respond to different treatments; chemotherapy is used less often for renal cell cancer than **transitional cell cancer**, for instance.

Chemotherapy causes your blood count to fall so you may be more prone to infections and tire easily. You may also feel sick, be sick or lose your hair. Some drugs make your mouth and throat sore. Ask your doctor or nurse about what to expect. There are drugs you can take to stop you feeling sick and mouthwashes you can use to prevent ulcers. The symptoms should stop when the treatment does. Your hair should grow back once the treatment is over if the treatment affected it initially.

All drugs used to treat cancer can affect fertility. If you are prescribed drugs they may only affect your ability to have children while you are taking them. However, with newer treatments the long-term effects may not yet be known, so this is an important issue to discuss with your doctor before you start treatment.

## Living with kidney cancer

### Feelings

If someone tells you that you have cancer it can be hard to take everything in. And it can be doubly hard if you are being told that your cancer has already spread so far it cannot be cured, or that a cancer you thought had gone has come back.

You will probably go through a whole range of emotions. Shock and fear. Sadness and anger. Disbelief. Numbness. You might find yourself thinking; why me? Or this can't be happening to me. There is no right or wrong way to feel; everyone reacts differently. Some people want to share their feelings and worries with their partner, their family or close friends. Others prefer to come to terms with the news first, before talking to others.

It's very common to wonder if things you did or didn't do in the past are to blame for your getting ill. But it isn't usually possible to tell exactly what caused a person's cancer and you may have to accept this. However, some people find they feel much less helpless and more in control if they learn as much as they can about the cancer itself and the ways it can be treated. Even if your cancer cannot be cured, there are ways of slowing it down or stopping it altogether for a time. The treatments can also help reduce or take away any symptoms you have been getting.

### Day-to-day living

Make sure you get help to feel as well as possible. Ask your doctor or nurse about referral to a **Macmillan nurse**. Macmillan nurses specialise in helping cancer patients. They are experts at controlling symptoms and often liaise between patients, relatives, GPs and the hospital to improve quality of life for the whole family. Some are qualified counsellors. **Marie Curie nurses** and healthcare assistants also provide support at home. For more information see page 29.

The body can manage perfectly well with one kidney. But it makes sense to look after the one you have left. So cut down on the amount of salt in your diet. Eat healthily. At all stages during your kidney cancer journey, a healthy, well-balanced diet will help you maintain strength and prevent infection. Good nutrition and maintaining calories is especially important when you are

undergoing intense treatments, such as surgery, radiotherapy and drug treatments. Foods rich in vitamins A and C, and high fibre foods to combat constipation are beneficial. Aim for more fresh fruit and vegetables and less protein-rich foods, such as meat, fish, eggs and dairy products. If you are a smoker, try to stop. Keep alcohol consumption to a minimum and drink plenty of water. And don't take large doses of vitamin C supplements.

Fatigue (tiredness) is one of the most distressing side effects of cancer. Fatigue may be caused by many factors, including depression, insomnia, anaemia, the effects of cancer treatment, and the cancer itself.

To help with fatigue, you need to pace your activities and organise your home and work environments in a way to help accommodate lower energy levels. You need to limit your physical activity before, during and after your treatment. Regular, gentle exercise and a healthy diet will help to reduce fatigue. As will relaxing activities, such as reading, listening to music, watching TV, and a nap during the day.

## **Palliative care**

Palliative care is the active total care of patients whose disease no longer responds to treatment. Palliative care attempts to make the end of a person's life as comfortable as possible by attempting to relieve pain and other distressing symptoms while providing psychological, social and spiritual support. Palliative care should not only be considered in the terminal phases of illness. You may need access to palliative care services almost from the point of diagnosis, particularly for help in dealing with social, spiritual and psychological issues. Carers and family may also be offered emotional and spiritual support.

Palliative care can be offered in your own home, in a hospice (residential or day care) or in hospital. If you decide to stay at home your GP or oncologist can arrange for community palliative care nurses, such as Macmillan or Marie Curie nurses, to provide care at home. The social services department may need to be contacted to provide a range of social care services and equipment to help you remain at home.

Specialist palliative care teams, such as the Macmillan support team, symptom control team or pain management team, provide palliative care in hospitals or hospices. These teams include doctors, nurses, physiotherapists, dieticians, social workers and chaplains, or the service can be provided by a specialist nurse.

## Money matters

A Macmillan nurse or your GP will be able to advise you about the grants that are available. These can be for mobility aids or to help with heating costs or household expenses related to your illness. A Macmillan nurse will also help you claim any benefits you are entitled to. Many hospital departments also have a social worker who can provide helpful information.

## Support

### Family and friends

People who are close to you may find it difficult to discuss your illness. And you may be afraid that if you talk to people about how you really feel they will be upset, or disappointed at your lack of stoicism, or embarrassed because they don't know what to say. But it is important to be able to express your feelings when you need to. It can also be difficult talking to children about cancer. How much should you tell them? How honest should you be? Macmillan and CancerHelp UK have some useful advice (see page 29).

### Other support

Sometimes it can be easier to talk things through with someone outside the family. This could be a specialist adviser or someone who has gone through a similar situation and knows how you are feeling. The James Whale Fund for Kidney Cancer can put you in touch with a volunteer to talk to or you can join the Kidney Cancer Support Network at [www.jameswhalefund.org](http://www.jameswhalefund.org). You could also call a **Macmillan nurse** on **0808 808 0000** or a **CancerHelp nurse** on **0808 800 4040**. If you leave a message out of hours someone will call you back.

## Self-help

Regular exercise can help you feel better both physically and emotionally. Ask your doctor or nurse what kind of exercise would be best. Many people find that alternative therapies, such as massage, aromatherapy, meditation or visualisation, can also lift the spirits, ease tension and restore a feeling of well-being. You can find out if any of these therapies are available near you by contacting New Approaches to Cancer, a UK charity (see page 29).

### Questions you might like to ask

- ? Where will I have my treatment?
- ? What will it involve?
- ? How long will it take?
- ? How will it affect me?
- ? What help will I get to deal with side-effects?
- ? Will I ever get back to normal or will there be some long-term effects?
- ? Will I be able to go back to work?
- ? What is the aim of this treatment?
- ? Will the treatment cure my cancer?
- ? Will the treatment stop the cancer growing? Or spreading?
- ? What are the risks of this treatment?
- ? What are the advantages of this treatment?
- ? What will happen if I don't have this treatment?
- ? Will I be able to manage with just one kidney?
- ? What happens if my other kidney stops working?
- ? What is the risk of getting cancer in the other kidney?
- ? What follow-up assessments will I have and when?
- ? How do I go about enrolling on a clinical trial?
- ? How do I get access to non-NHS drugs if I need them?
- ? Are there any local support groups at the hospital or in my area?

## Where to find more information

Help, information and support can also be found at local hospital-based support groups. Please ask your doctor or nurse for more information.

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**James Whale Fund for Kidney Cancer** is the UK's leading specialist kidney cancer charity. It seeks to help reduce the harm caused by kidney cancer by increasing knowledge and awareness, providing information and by supporting research into the causes, prevention and treatment of the disease.

- 📞 Call **0844 474 5050** (10am-4pm, Mon-Fri)
  - 🌐 or visit **[www.jameswhalefund.org](http://www.jameswhalefund.org)**
- 

**The Kidney Cancer Support Network** is a patient forum for the exchange of ideas and information between carers and patients throughout the UK. The forum appears on a dedicated website which the James Whale Fund has helped set-up and fund. However, the forum is not under the control of the James Whale Fund.

- 🌐 Visit **[www.kidneycancersupportnetwork.co.uk](http://www.kidneycancersupportnetwork.co.uk)**

The following map will help you to find kidney cancer sufferers in your region;

- 🌐 **[www.kidneycancersupportnetwork.co.uk/map.php](http://www.kidneycancersupportnetwork.co.uk/map.php)**
- 

**Kidney Cancer Careline** is a telephone helpline supported by the James Whale Fund for Kidney Cancer, which provides practical information, support and encouragement for people with kidney cancer and their families. The careline is operated by a panel of cancer patients who can draw on their own experience of the kidney cancer treatment pathway to support and encourage patients and their families during the difficult time following a diagnosis of kidney cancer.

- 📞 Call **0330 111 2 333** to speak to a member of the Patient Support Team.
- 🌐 Visit **[www.kidneycancercare.org.uk](http://www.kidneycancercare.org.uk)**
- ✉ Email **[kcc@jameswhalefund.org](mailto:kcc@jameswhalefund.org)**



**Kidney Cancer Bloggers** is a chat forum for kidney cancer sufferers and their families and friends to share experiences, thoughts and information.

- 🌐 Visit **[www.kidneycancerbloggers.com](http://www.kidneycancerbloggers.com)**
-

**Kidney Cancer UK** aims to provide UK kidney cancer patients and their carers with improved access to reliable information about kidney cancer and its treatment, and to establish a network of individuals and groups capable of offering mutual support.

 Visit [www.kcuk.org](http://www.kcuk.org)

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**KIDNEY-ONC** is an e-mail discussion group for patients with kidney cancer, their family and friends. Health professionals with an interest in this area are also encouraged to join.

 Visit [www.cancerguide.org/kofaq](http://www.cancerguide.org/kofaq)

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**Cancer Research UK** is the largest cancer research organisation in the world. One of its websites is CancerHelp UK, a free information service about cancer and care for people with cancer and their families.

 Call CancerHelp nurses on **0808 800 4040** (9am-5pm, Mon-Fri)

 or visit [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

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**Macmillan Cancer Support** helps people living with cancer and their family, friends and carers find a way through the maze of cancer support and information in the UK.

 Call Macmillan nurses on **0808 808 0000** (9am-8pm, Mon-Fri)

 or visit [www.macmillan.org.uk](http://www.macmillan.org.uk)

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**Marie Curie Cancer Care** runs hospices throughout the UK and provides a nationwide Marie Curie nursing service. Marie Curie nurses provide free nursing care to cancer patients and those with other terminal illnesses in their own homes.

 Call the help line for patients and carers on **0800 716 146**

 or visit [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

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**New Approaches to Cancer** promotes the benefits of using complementary therapies alongside conventional medical treatments. Their services are free of charge and they provide a range of information on experienced holistic practitioners and clinics nationwide.

 Call **0800 389 2662**

 or visit [www.anac.org.uk](http://www.anac.org.uk)

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## Glossary

### Adjuvant therapy

A treatment given in addition to the main treatment (for example, biological therapy as well as surgery) to try to prevent a cancer from coming back.

### Advanced cancer

This usually means a cancer that has spread from where it started to another part of the body. 'Locally advanced' cancer usually means the cancer has grown outside the organ that it started in and into nearby body tissues.

### Angiogenesis

Growth of blood vessels. Growing cancers can attract new blood vessels to grow towards them so that they can get their own blood supply.

### Anti-angiogenic agents

Agents which interfere with the development of blood vessels.

### Arterial embolisation

A procedure in which the blood supply to the area of the kidney containing the tumour is blocked causing it to shrink.

### Bilateral renal cell carcinoma /kidney cancer

Renal cell carcinoma or kidney cancer affecting both kidneys.

### Biological therapy

Treatment that uses natural body substances or drugs made from natural body substances to treat cancer.

### Biopsy

Removal of a small piece of body tissue so that the cells can be looked at under a microscope.

### Birt-Hogg-Dubé (BHD) syndrome

A rare inherited genetic condition that is characterised by skin lesions on the face and neck. It is caused by a genetic mutation in the folliculin gene. Patients may also develop lung cysts or experience a collapsed lung, and a few develop kidney cancer.

### Bone scan

A diagnostic test using a mildly radioactive material to see whether the cancer has spread to your bones.

### Catheter

Tube that is passed into the body to drain fluid.

### Cells

Every part of the body is made up of specialised, individual cells. Cancer starts with one cell becoming cancerous.

### Chemotherapy

The use of anti-cancer or cytotoxic drugs to destroy cancer cells.

### Clear cell RCC

A type of renal cell carcinoma which originates in the lining of the kidney tubules.



## **Clinical Nurse Specialist (CNS)**

An advanced practice nurse with a graduate qualification; clinical experts in the diagnosis and treatment of illness.

## **Combination therapy**

Using two or more types of treatment eg surgery and chemotherapy or chemotherapy and radiotherapy.

## **Computerised tomography (CT)**

A special type of X-ray examination in which a series of X-ray pictures of your body are taken from different angles and put together by a computer to give a detailed image of the inside of your body.

## **Contrast agent**

A special dye which is given during and X-ray, CT or IVU/IVP as an injection or in a drink. Contrast agents are opaque to X-rays and are used to give soft tissues and blood vessels contrast on an X-Ray so that they can be seen.

## **Cryotherapy**

A method of killing cancer cells by freezing the tumour using a probe through the skin to avoid open surgery.

## **Cyst**

A closed sac which may contain air, fluids, or semi-solid material. Once formed, a cyst could go away on its own or may have to be removed through surgery. Most cysts are benign but some are formed within tumours and may be malignant (cancer).

## **Cystoscopy**

An investigation of the bladder. A surgeon puts a tube (or cystoscope) into the bladder and uses it to look inside the bladder and urethra to check if there is anything wrong.

## **Cytotoxic**

Substances which are toxic to cells.

## **Diagnosis**

Finding out what is wrong.

## **Dialysis**

An artificial way of filtering waste products and excess water from your blood when your kidneys can't.

## **Fractions**

Daily radiotherapy treatments.

## **Full blood count (FBC)**

A blood test which provides important information about the type, number and appearance of cells in the blood, especially red blood cells, white blood cells, and clotting cells.

## **Gamma knife surgery (stereotactic radiosurgery or radiosurgery)**

Radiotherapy for brain metastases using high doses of radiation directed at the cancer using a head frame.

## **Grade**

Doctors grade cancers to indicate how quickly or slowly a cancer is likely to grow and spread. Cells from a sample of the cancer (a biopsy) are looked at under the microscope or tested in other ways.

## **Haematuria**

The presence of blood in the urine.

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

A method of killing cancer cells by directing a strong beam of sound at the tumour. This technique is done using a probe through the skin thereby avoiding open surgery.

## **Hypercalcaemia**

High levels of calcium in the blood.

## **Hypertension**

High blood pressure.

## **Immunotherapy**

A method to treat cancer using man-made copies of substances found naturally in the body which stimulate the body's own immune system to attack the cancer cells.

## **Intravenous Urogram (IVU) or Intravenous Pyelogram (IVP)**

A special X-ray examination of your urinary system.

## **Laparoscopic nephrectomy**

Keyhole surgery to remove the kidney through a small cut in the abdomen. Laparoscopic nephrectomy can be carried out for patients for whom open surgery is not an option.

## **Lymph nodes or glands**

Glands which fight infection and filter body fluid (lymph).

## **Magnetic resonance imaging (MRI)**

A type of scan that uses magnetism instead of X-rays to construct a detail picture of the inside of your body.

## **Mammalian target of rapamycin (mTOR) inhibitors**

Protein kinase inhibitors which are used to treat cancer by interfering with the signalling pathway that controls tumour cell growth and angiogenesis.

## **Metastases or secondaries**

Areas of cancer spread.

## **Monoclonal antibody**

Antibodies which specifically bind to signalling proteins which control various biological functions, such as angiogenesis, and interfere with their actions.

### **Multidisciplinary team (MDT)**

A group of health care and social care professionals who provide different services for patients in a co-ordinated way. Members of the team may vary and will depend on the patient's needs and the condition or disease being treated.

### **Nephrectomy**

Surgical removal of a kidney. Either radical (the whole kidney and surrounding tissues) or partial. [Gr nephros, a kidney].

### **Neuropathic pain**

Pain that comes from problems with the signalling from nerves.

### **Oncology and oncologist**

The study and treatment of cancer. An oncologist is a doctor who specialises in the diagnosis and treatment of cancer.

### **Palliative care**

Treatment given to control symptoms and improve quality of life rather than to cure. Includes support for social, spiritual and psychological issues.

### **Physical examination**

The process by which a doctor investigates the body of a person for signs of disease.

### **Polycythaemia**

Thickening of the blood caused by an increase in red blood cells due to an abnormality in the bone marrow, or a decrease in the volume of plasma, the fluid which carries the red blood cells.

### **Positron emission tomography (PET)**

A diagnostic test using mildly radioactive form of glucose to find malignant tumours.

### **Primary cancer (primary tumour)**

Where the cancer started. The type of cell that has become cancerous will be the primary cancer; for example, if a biopsy from the liver or lung contains cancerous kidney cells, then the primary cancer is kidney cancer.

### **Prognosis**

The likely outlook for someone with a disease.

### **Protein kinase inhibitors**

Small molecules that work inside the cell to inhibit kinases - proteins which are part of the signalling system that tells cells when to divide and grow and produce new blood vessels.

### **Quality of life**

This means looking at how a treatment is affecting your life, not just the effect on your cancer.

### **Radio-frequency ablation (RFA)**

A method of killing cancer cells using heat from an electric probe through the skin, thereby avoiding the need for open surgery.

## **Radiotherapy**

A treatment using high-energy rays to destroy cancer cells. It can be used to shrink a kidney cancer and so control symptoms.

## **Radiosurgery (or stereotactic radiotherapy or gamma knife surgery)**

Radiotherapy for brain metastases using high doses of radiation directed at the cancer using a head frame.

## **Recurrence**

Cancer that has come back again after treatment.

## **Remission**

If a cancer is in remission, there is no sign of it on scans or when the doctor examines you. Doctors use the word ‘remission’ instead of cure when talking about cancer because they cannot be sure that there are no cancer cells at all in the body.

## **Renal cell carcinoma (RCC)**

A kidney cancer that originates in the lining of the proximal convoluted tubule, the very small tubes in the kidney that filter the blood and remove waste products.

## **Staging**

A system used by doctors to describe how big a cancer is and how far it has already spread.

## **Stereotactic radiotherapy (or radiosurgery or gamma knife surgery)**

Radiotherapy for brain metastases using high doses of radiation directed at the cancer using a head frame.

## **Tyrosine kinase inhibitors (TKI)**

Small molecules that work inside the cell to inhibit tyrosine kinases - proteins which are part of the signalling system that tells cells when to divide and grow and produce new blood vessels.

## **Tumour**

A swelling or lesion formed by an abnormal growth of cells. Tumour is not synonymous with cancer and a tumour can be benign (not cancerous) or malignant (cancerous).

## **TNM staging**

A system for staging cancer based on the presence of tumours (T), lymph node involvement (N) and metastases (M).

## **Transitional cell carcinoma (TCC)**

A type of cancer that develops in the lining of the bladder, urethra and renal pelvis.

## **Ultrasound scan**

A real-time, moving test which uses sound waves to detect and differentiate between tumours and cysts. A small probe producing sound waves is rubbed over the area of interest and the sound wave echoes are detected by the probe and turned into a picture of the organs and structures inside your body by a computer.

## **Urea and electrolytes (U&E)**

A blood test which tests the function of the kidneys.

## **Urology and urologist**

The study and treatment of the urinary tract in women and the urogenital system in men. A urologist is a doctor who specialises in the diagnosis and treatment of diseases of the urinary and sex organs in males and the urinary organs in females.

## **Vaccine**

Naturally occurring substances which stimulate the body's immune system to fight disease.

## **Vascular endothelial growth factor (VEGF)**

A naturally occurring protein which is part of the signalling pathway that helps cancers to grow blood vessels.

## **Von Hippel-Lindau (VHL) syndrome**

A rare inherited genetic condition which causes abnormal growth of blood vessels. VHL is caused by a genetic mutation in the VHL gene and about 28-45% of VHL patients develop kidney cancer. VHL kidney cancer is only clear cell and it can metastasise and become aggressive.

## **Wilms' tumour**

A very rare kidney cancer which affects children.

## **X-ray**

A type of electromagnetic radiation used to make images. The image is recorded on a film, called a radiograph. The parts of your body appear light or dark due to the different rates that your tissues absorb the X-rays. Calcium in bones absorbs X-rays the most, so bones look white on the radiograph. Fat and other soft tissues absorb less, and look gray. Air absorbs least, so lungs look black.

## Notes

Kidney Cancer Careline - 0330 111 2 333

Patient Forum - [kidneycancersupportnetwork.co.uk](http://kidneycancersupportnetwork.co.uk)

James Whale Fund - [jameswhalefund.org](http://jameswhalefund.org)

# The help button for kidney cancer patients



Click on [www.jameswhalefund.org](http://www.jameswhalefund.org) to discover a wealth of information on kidney cancer for patients and carers. Speak to carers and patients, join a forum to swap experiences, visit our on-line shop and much more...

*The UK's leading specialist kidney cancer charity*

# James Whale Fund for Kidney Cancer

The Fund was set up in 2006 by broadcaster James Whale who lost a kidney to cancer six years earlier. Our mission is to help reduce the harm caused by kidney cancer by increasing knowledge and awareness, providing patient information and by supporting research into the causes, prevention and treatment of the disease.

## Help our cause

The Fund's ability to achieve its aims is dependant on the support it receives from the general public. If you would like to make a donation, you can do so in the following ways:

Make a donation online by visiting [www.jameswhalefund.org](http://www.jameswhalefund.org)

Send a cheque made payable to '**James Whale Fund**' to  
**James Whale Fund for Kidney Cancer, 46-48 King Street Cambridge CB1 1LN**

Make a credit or debit payment (except Diners) on the phone,  
by calling **0844 474 5050**

Send a donation to the James Whale Fund Bank account at Barclays  
with your name as reference.

Sort Code **20-17-35**

Account **800 98094**

If you would like to offer your support in other ways, we'd be very  
pleased to hear from you.

A large text version of this document is  
available. Please contact the James Whale  
Fund for Kidney Cancer for copies.

This booklet was produced with the help of  
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