

# Understanding Kidney cancer

A patient information guide from the James Whale Fund for Kidney Cancer

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



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If you are reading this booklet, 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 and your family and friends through this difficult time and will help you to 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.

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 James Whale Fund for Kidney Cancer patient forum at [www.jameswhalefund.org](http://www.jameswhalefund.org) or call the **Kidney Cancer Careline** on **0330 111 2 333**.

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...

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

## Kidney Cancer

Every year in the UK, over 10,000 people learn that they have kidney cancer<sup>1</sup>. The incidence of kidney cancer has been steadily increasing in the UK, mainly attributed to lifestyle factors, such as obesity and smoking. In addition, an increase in the number of tumours detected when a patient has a scan for an unrelated condition may have also contributed to the rise in the number of kidney cancer cases. Kidney cancer is now the eighth most common cancer in the UK and accounts for 3% of all new diagnoses of cancer; it is the seventh most common type of cancer among men and tenth among women<sup>1</sup>.

### Risk factors for kidney cancer

Kidney cancer more often affects older men, who usually appear healthy; about three quarters (75%) of people diagnosed with kidney cancer are over 60 years old and nearly twice as many men are diagnosed than women<sup>1</sup>. It is not unusual to discover a tumour on the kidney incidentally whilst the patient is having a scan for an unrelated condition. It is rare for people under 40 to be diagnosed with kidney cancer<sup>2,3</sup>.

The risk of developing kidney cancer starts to rise around 45-49 years and is highest in people aged 80-84<sup>1</sup>. Other factors that can predispose people to the disease are; an unhealthy diet (obesity), smoking, genetic factors (such as a mutation

### RISK FACTORS FOR KIDNEY CANCER:

- Age; the risk of developing kidney cancer increases with increasing age
- Unhealthy diet (obesity)
- Smoking
- Gender; men are nearly twice as likely to develop kidney cancer than women
- Hereditary genetic syndromes, such as **von Hippel-Lindau**, **Birt-Hogg-Dubé**, tuberous sclerosis and hereditary clear cell and papillary renal cell cancer, caused by inherited faulty genes
- Long term use of mild painkillers, such as ibuprofen (Nurofen®)
- Long term kidney dialysis
- Hypertension
- Previous thyroid cancer
- Previous radiotherapy for testicular or cervical cancer

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 long-term use of non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Nurofen®), may slightly increase the risk of kidney cancer, as will radiotherapy for previous testicular or cervical (neck of the womb) cancer. People on long term kidney dialysis, people who have had thyroid cancer, and people with hypertension are also at greater risk<sup>2,3</sup>.

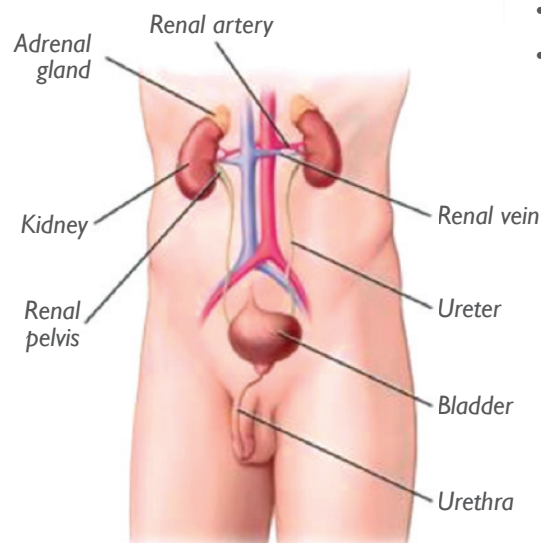
A risk factor is anything that increases a person's chance of developing cancer. Although risk factors can influence the development of cancer, most do not directly cause cancer. Some people with several risk factors never develop cancer, while others with no known risk factors do. However, knowing your risk factors and talking about them with your doctor may help you make more informed lifestyle and health care choices.

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. Other symptoms can be less specific such as tiredness or pain. Some patients get no symptoms at all and the cancer is found incidentally.

### Types of kidney cancer

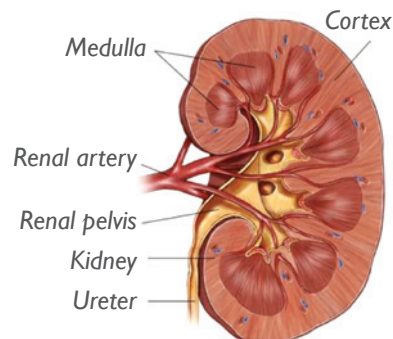
The most common form of kidney cancer is **renal cell carcinoma** or RCC for short. About 90% of kidney cancers are RCCs. There are several different subtypes of RCC, which are named according to the type of cell that is affected or the appearance of the cancer cells under the microscope. The most common of these is **clear cell**, which account for about 75% of RCCs. Other subtypes include **papillary**, **chromophobe**, and **collecting duct carcinoma**<sup>4</sup>.

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 **transitional cell carcinoma**, **Wilms' tumour**, which affects young children, and hereditary kidney cancer syndromes, such as **von Hippel-Lindau**, **Birt-Hogg-Dubé**, and **tuberous sclerosis** can be obtained from our website [www.jameswhalefund.org](http://www.jameswhalefund.org) or from Cancer Research UK [www.cancerresearchuk.org](http://www.cancerresearchuk.org) or Macmillan Cancer Support [www.macmillan.org.uk](http://www.macmillan.org.uk) (see page 34).



## SUBTYPES OF RENAL CELL CARCINOMA (RCC):

- Conventional or clear cell RCC – this can also be called non-papillary RCC and accounts for 75% of RCC cases. The cancer cells appear clear under the microscope and have large nuclei.
- Papillary or chromophilic RCC accounts for about 10-15% of RCC cases. The tumours have characteristic papillae or nodules on the surface.
- Chromophobe RCC accounts for about 5% of cases
- Collecting duct carcinoma
- Renal medullary carcinoma
- Mucinous tubular and spindle-cell carcinoma
- Renal translocation carcinomas
- Unclassified RCC, the latter five of which together make up the remaining 5-10% of RCC tumours



## Getting a Diagnosis

### The symptoms of kidney cancer

The most common symptom is blood in the urine<sup>5,6,7</sup>. 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.

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 pain in your side between your ribs and hipbone (sometimes called the flank or loin)<sup>5,6,7</sup>. The sooner kidney cancer is detected, the easier it is to treat.

In the early stages of kidney cancer there may be no obvious symptoms<sup>6,7</sup>. 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, and high levels of calcium in the blood (**hypercalcaemia**)<sup>5,6,7</sup>.

Sometimes abnormal red blood cell counts and high blood pressure, or **hypertension**, can be symptoms of kidney cancer<sup>5</sup>. Some patients experience a condition called **polycythaemia**, or thickening of the blood, which can also be a symptom of kidney cancer. Symptoms of polycythaemia are a bad headache and redness of the skin<sup>8</sup>.

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 (or **haemoptysis**), abnormal liver function tests, headaches and visual disturbances, or bone pain<sup>6,8</sup>. 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, such as weight loss, tiredness and running a persistent temperature and sweating heavily, especially at night<sup>6,7,8</sup>.

## How doctors diagnose kidney cancer

Currently, there are no screening programmes for kidney cancer in the UK. Doctors use their clinical experience (clinical suspicion), scans, and various tests to identify kidney cancer<sup>7,9,10</sup>.

### AT YOUR GP SURGERY

Your family doctor or GP will probably carry out some initial tests. 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.

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.

## TYPICAL SIGNS AND SYMPTOMS OF KIDNEY CANCER

- Blood in the urine, also called haematuria
- Persistent low back pain or pain in the side between the ribs and hipbone
- A lump or mass in the area of the kidneys
- Abnormal red blood cell counts
- High blood pressure or hypertension
- Thickening of the blood (polycythaemia)
- Tiredness
- Weight loss and/or loss of appetite
- Running a persistent temperature and sweating heavily, especially at night

### AT HOSPITAL

The hospital specialist, usually an **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 test the function of your kidneys. If you want to know the results of your blood tests, please ask your doctor to explain them.

### ULTRASOUND SCAN

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 that is done in the hospital scanning department, and only takes a few minutes to perform. You lie down and gel is spread on your tummy. 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.

### CYSTOSCOPY

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.

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.



## 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. A computer puts these images together 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 beforehand. 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 scan but will be able to see you on a monitor and talk to you through an intercom. You may be given an injection of a special dye, or **contrast agent**, into a vein in your arm 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.

## 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. You will need to be observed for about 4 hours after the biopsy.

## 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 in your arm to help the tumours show up more clearly on the MRI scan picture.

## 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 page 34.

### TYPICAL DIAGNOSTIC TESTS

- Ultrasound scan
- CT scan
- Biopsy
- MRI
- Bone scan
- Chest X-ray
- Intravenous urogram/pyelogram (IVU/P)
- Cystoscopy

## 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 the kidney cancer pages of the Cancer Research UK website [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk) if you choose to (look for the Outlook and Stats page). 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.

## 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?

## Having Treatment

Before your doctors can discuss treatment options with you they need to know how far your cancer has progressed and how quickly the cancer is growing or spreading. This is called staging and grading.

### Staging and grading kidney cancers

**Staging** is used to describe how big a cancer is and how far it has already spread. Information from the tests and scans used to diagnose your cancer is used to determine the stage of your disease.

The **TNM system** is a common system used for staging tumours<sup>11,12</sup>;

**T** (tumour) plus a number indicates the size of the **primary tumour** and how far it has grown: The number refers to the stages described below:

**T0** – there is no evidence of primary tumour in the kidney

**T1** – the tumour is less than 7 cm in size and is completely contained within the kidney

**T1a** is a tumour less than 4 cm in size

**T1b** is a tumour between 4 and 7 cm in size

**T2** – the tumour is more than 7 cm in size and is completely contained within the kidney

**T2a** is a tumour more than 7 cm but less than 10 cm in size

**T2b** is a tumour more than 10 cm in size

**T3** – the cancer has spread beyond the kidney to the tissues or organs around the kidney, for example a major vein or the adrenal gland

**T3a** is a tumour that has grown into the renal vein or the fat surrounding the kidney

**T3b** is a tumour that has grown into the vena cava below the diaphragm

**T3c** is a tumour that has grown into the vena cava, or the wall of the vena cava, above the diaphragm

**T4** – the cancer has spread beyond the tissues or organs around the kidney to more distant organs in the body

**N** (nodes) plus a number indicates that the cancer has spread to nearby lymph nodes. The number refers to the number of affected lymph nodes:

**N0** – cancer has not been detected in any lymph nodes

**N1** – cancer has spread to one nearby lymph node only

**N2** – cancer has spread to more than one nearby lymph node

**M** (metastases) plus a number refers to places elsewhere in the body where the cancer has spread. M0 means there are no distant metastases and M1 means distant metastases are present.

Your doctor will combine these figures to give an overall staging, e.g. T2 N0 M0, 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 to the adrenal gland or a major vein nearby. The cancer may have spread to no more than one nearby lymph node.
- **Stage 4** - the cancer has spread to nearby tissues or organs and more than one nearby lymph node contains cancer cells OR the cancer has spread 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**) for your cancer. 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; this system is called the **Fuhrman system**<sup>12,13</sup>:

- **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 grade 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.

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.

## Discussing treatment options

Ideally, a team of specialists, called a **multi-disciplinary team** (MDT), will be responsible for your care and treatment in the cancer unit. The team will include an **urologist** (a doctor who specialises in diagnosing

## THE MULTI-DISCIPLINARY TEAM (MDT)

- Urologist
- Medical oncologist (for medical therapy)
- Clinical oncologist (for radiotherapy)
- Clinical Nurse Specialist
- Dietitian
- Physiotherapist
- Occupational Therapist
- Psychologist
- Counsellor



and surgically treating urinary, bladder and kidney problems) and, if your cancer has spread, a **medical oncologist** who specialises in the medical treatment of cancer. Preferably, both will have experience of treating kidney cancer. The urologist and, if appropriate, the medical oncologist will be responsible for your treatment and will discuss your treatment plan with you.

Other members of the team may include a **clinical nurse specialist** (specialist nurse), a dietitian, a physiotherapist (for postoperative complications), an occupational therapist and a psychologist or counsellor. The team might also include a **clinical oncologist** (a doctor specialising in radiotherapy treatment for cancer) if you are scheduled to have radiotherapy for cancer that has spread.

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. There is more information about how to get a second opinion on the NHS Choices website (<http://www.nhs.uk/chq/pages/910.aspx>)

You may find the decision to go ahead relatively easy, if the treatment you are being offered aims to cure your cancer. 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 31 for more on palliative care.

## Surgery

Surgery to remove the affected 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 remove metastases in some cases of advanced kidney cancer.

### PARTIAL NEPHRECTOMY

Removing part of the kidney containing the tumour is called a **partial nephrectomy** or **kidney/nephron sparing surgery**. The aim of this surgery is to remove the whole tumour while leaving as much normal tissue as possible. It means that some working kidney is left behind. For this reason, partial nephrectomy is carried out for people

who only have one kidney, who have kidney disease or who have tumours in both kidneys. Specialist surgeons now treat most early stage (stage I) kidney tumours that are less than 7 cm in size with partial nephrectomy, if possible<sup>12</sup>.

## RADICAL NEPHRECTOMY

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 or a kidney transplant.

A radical nephrectomy may be carried out using open surgery, during which the surgeon usually makes a large incision or cut below the lower ribs on the side of the affected kidney. The whole kidney and surrounding tissues are removed through this incision.

## KEYHOLE (LAPAROSCOPIC) AND ROBOTIC SURGERY

Sometimes it is possible to use keyhole surgery or **laparoscopic nephrectomy** to remove the affected kidney, for which you will need a referral to a specialist urological surgeon with particular experience in laparoscopic kidney surgery. Laparoscopic surgery can also be used to carry out a partial nephrectomy.

Laparoscopic nephrectomy can be used when open surgery is not an option, for example patients with high blood pressure. The operation is carried out using several small incisions or cuts in the skin of the tummy (abdomen), rather than one large incision. A thin tube with a camera and a light at the end is inserted into the abdomen through one of the cuts. This instrument is called a laparoscope and it enables the doctor to see inside your tummy. Other small instruments are inserted through the other cuts and used to remove the kidney or part of the kidney containing the tumour.

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.

**Assisted robotic surgery** is a type of laparoscopic surgery in which a special machine or robot is used by the surgeon to help carry out the surgery. The surgeon has a 3D view of the inside of your tummy and the area can be magnified 10-12 times. Robotic surgery is only available at a few specialist centres in the UK.

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<sup>14</sup>.

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 (specialist nurse) about this<sup>14</sup>.

A nephrectomy is a major operation and, as with any operation, there can be some risks, such as infection or blood clots (thrombosis) in the legs, arms or chest. If you are concerned by any of these, or if you have any symptoms of an infection (fever, feeling generally unwell) or a wound infection (redness, pain, swelling and oozing from the wound), please see your doctor<sup>14</sup>.

Some people may find the scarring or changes to their body and how it works difficult to deal with. Some may have concerns about the effects of the operation on relationships. You may need support to enable you to cope with such



changes. Please talk to your doctor or nurse about how you feel and they will be able to put you in touch with somebody who can help.

You should get a follow up outpatient appointment to check your recovery six weeks after your surgery where your consultant should discuss with you your **prognosis** and/or treatment options and follow-up schedule.

## FOLLOW-UP AFTER SURGERY

There are no guidelines for the method and timing of follow-up examinations after surgery. You will be followed-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<sup>15</sup>.

## Other surgical treatments

Doctors have been researching less invasive ways of removing kidney tumours. These treatments can be used to remove small tumours (less than 4 cm in size) and for people who are unable to have surgery. They may also be used to treat people with multiple kidney tumours or tumours in both kidneys (bilateral disease).

## CRYOTHERAPY

**Cryotherapy** kills the cancer cells by freezing the tumour; however, there are only limited data to prove how effective this procedure is. The doctor inserts one or more fine needles or probes through the skin (**percutaneous**) and into the tumour. Argon gas or liquid nitrogen is passed through the needles under pressure to freeze

the tumour. Regular CT scans are carried out during the procedure to ensure the needles are positioned correctly in the tumour and the entire tumour has been frozen. Cryotherapy is usually carried out under general anaesthetic, or sedation if a general anaesthetic is not suitable. Cryotherapy can also be carried out using keyhole surgery<sup>16,17</sup>.

Complications or side effects after cryotherapy include pain, infection and bleeding. A small number of people experience damage to the bowel and a blockage or damage to the **ureter**, the tube from the kidney to the bladder through which urine passes. However, in specialist centres that perform a lot of cryotherapy procedures, these complications are minimal<sup>16,17</sup>.

National Institute for Health and Care Excellence (NICE) has issued guidance for percutaneous cryoablation<sup>18</sup>; however, this procedure is only available at a few specialist centres in the UK. Further research is needed to compare the long-term outcomes of cryotherapy with those of other treatments for kidney cancer.

## RADIOFREQUENCY ABLATION

**Radiofrequency ablation (RFA)** uses heat from an electric probe to destroy the tumour; however, there are only limited data to prove how effective this procedure is. Fine needles are inserted through the skin (percutaneous) and into the tumour. An electric current is passed through the needles to heat the cancer cells and destroy them. Regular CT or ultrasound scans are carried out during the procedure to ensure the needles are positioned correctly. RFA is usually carried out using local anaesthetic and sedation, and can also be carried out using keyhole surgery<sup>19,20</sup>.

Complications or side effects after RFA include pain, infection and bleeding. A small number of people

## SURGICAL TREATMENTS

- Partial nephrectomy (open or keyhole)
- Radical nephrectomy (open or keyhole)
- Laparoscopic (keyhole) surgery or robot assisted surgery
- Cryotherapy
- Radiofrequency ablation (RFA)
- High intensity focussed ultrasound (HIFU)

experience damage to the kidney causing urine leakage and a narrowing of the ureter, making it difficult to pass urine. However, in specialist centres that have a lot of experience of RFA procedures, these complications are minimised<sup>19,20</sup>.

National Institute for Health and Care Excellence (NICE) has issued guidance for percutaneous RFA<sup>21</sup>; however, this procedure is only available at a few specialist centres in the UK. Further research is needed to compare the long-term outcomes of RFA with those of other treatments for kidney cancer.

## HIGH INTENSITY FOCUSED ULTRASOUND

**High intensity focused ultrasound (HIFU)** directs strong beams of sound at the tumour, which heats up the cancer cells and kills them. HIFU is only available in clinical trials for the treatment of kidney cancer in the UK, and research is on going to determine the effectiveness of this technique. HIFU can be carried out under general or local anaesthetic and side effects include pain, bleeding and infection<sup>20,22</sup>.

The main advantage of cryotherapy, RFA and HIFU is that they can be done using probes through the skin so you don't have to have 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. These treatments may be repeated if not successful first time.

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 **targeted therapy** or a course of **radiotherapy**. Your doctor or clinical nurse specialist (specialist nurse) will discuss this with you.

## 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.

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 disease. You can get more information about clinical trials from the James Whale Fund for Kidney Cancer and Cancer Research UK (see page 34).

Several different types of biological therapy are used for the treatment of advanced kidney cancer, including **immunotherapies**, **targeted therapies** and **monoclonal antibodies**.

## IMMUNOTHERAPIES

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. These immunotherapies are not often used for the treatment of kidney cancer any more, as other drugs are more effective. New immunotherapies, such as PD-1 inhibitors, are being tested.

**Interferon alpha-2a** (Roferon-A<sup>®</sup> or IntronA<sup>®</sup>) works by helping to stop the cancer cells from growing, and by boosting the immune system to attack the cancer. 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<sup>23,24</sup>.

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, sickness, diarrhoea, loss of appetite, low blood pressure (that can make you feel dizzy or faint), feeling sad or depressed, and tiredness. The side effects tend to lessen as the treatment continues<sup>23,24</sup>.

**Interleukin-2** or **aldesleukin** (Proleukin®) stimulates a type of white blood cell, called T-lymphocytes, to attack the cancer. T-lymphocytes are part of the immune system. It is usually given through a drip into a vein in the arm. Treatment is given in a series of cycles of 5 days followed by a break in treatment for a few days or weeks. The side effects are similar to those of interferon, but are likely to be worse and vary depending on the dose<sup>23,24</sup>.

The most common side effects include; chills, fever, headache, aches and pains, nausea and vomiting, and loss of appetite. Interleukin-2 may also cause changes to the pattern of your heartbeat, fluid on the heart or lungs, or problems such as low blood pressure and swollen hands and feet. 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<sup>23,24</sup>.

Immunotherapy, such as interferon-alpha and interleukin-2, used to be the main treatments for advanced kidney cancer. However, their use has been superseded by targeted therapies, which are more effective at controlling the cancer and have less severe side effects. As a result, the use of immunotherapy for advanced kidney cancer has declined in recent years<sup>25</sup>. However, a small minority of patients (about 5%) who are otherwise healthy and well enough to withstand the severe side effects have a long-term durable response to high doses of interleukin-2. Interleukin-2 therefore still has a place in the treatment of a small percentage of patients where it offers the hope of durable remission<sup>26</sup>.

#### POTENTIAL SIDE EFFECTS TO TARGETED THERAPIES

- Tiredness
- Diarrhoea
- Nausea and vomiting
- Skin and hair discolouration/changes
- Red and blistered hands and feet (palmar-plantar erythrodysesthesia, PPE)
- Sore mouth
- Raised blood pressure
- Thyroid problems
- Blood problems (sunitinib)
- Loss of taste and appetite

#### TARGETED THERAPIES

Cancer researchers have been working to find new ways of stopping kidney cancers growing and spreading. One of the most promising advances has been the development of targeted therapies, such as **tyrosine kinase inhibitors (TKIs)** and **mammalian target of rapamycin (mTOR) inhibitors**. These drugs are now standard treatment for advanced kidney cancer.

Tyrosine kinase inhibitors (TKIs), such as **sunitinib (Sutent®)**, **sorafenib (Nexavar®)**, **pazopanib (Votrient®)**, and **axitinib (Inlyta®)** block the effects of a protein called tyrosine kinase, which is 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**. Tyrosine kinase inhibitors also interfere with the growth of cancer cells by blocking the signals within the cancer cells that tell them to grow and divide, causing the cancer cells to die<sup>23-25</sup>.

Tyrosine kinase inhibitors come as tablets or capsules that you swallow. Sunitinib comes as a capsule, which is taken once a day for four weeks followed by a two week break. Pazopanib, sorafenib and axitinib are tablets that are usually taken once or twice a day for as long as the treatment is helping<sup>23-25</sup>.

The most common side effects included; tiredness, stomach upsets from diarrhoea to nausea and vomiting, skin and hair discolouration/changes, red and blistered hands and feet, sore mouth, an increase in blood pressure, thyroid problems, blood problems, 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<sup>23-25</sup>.

Your clinical nurse specialist (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, sunitinib and pazopanib are used as **first-line treatment** for advanced RCC. Axitinib, pazopanib or sorafenib are 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. Axitinib is also recommended for use as **second-line treatment** after sunitinib has stopped working or if the patient cannot tolerate this treatment<sup>12</sup>.

Although sunitinib, pazopanib, axitinib and sorafenib have all been licensed for the treatment of people with advanced kidney cancer, the National Institute for Health and Care Excellence (NICE) have issued guidance that recommends only sunitinib and pazopanib as first-line treatment options in NHS hospitals. No second-line treatment options have been recommended by NICE<sup>27,28</sup>. However, in addition to sunitinib and pazopanib as first-line treatment, the Scottish Medicines Consortium

## DRUG TREATMENTS AVAILABLE ON THE NHS

- Interferon alpha-2a (Roferon-A<sup>®</sup> or IntronA<sup>®</sup>)
- Interleukin-2 or Aldesleukin (Proleukin<sup>®</sup>)
- Sunitinib (Sutent<sup>®</sup>)
- Pazopanib (Votrient<sup>®</sup>)

## DRUG TREATMENTS LICENSED FOR USE BUT NOT AVAILABLE ON THE NHS

- Sorafenib (Nexavar<sup>®</sup>)
- Axitinib (Inlyta<sup>®</sup>)
- Bevacizumab (Avastin<sup>®</sup>)
- Everolimus (Afinitor<sup>®</sup>)
- Temsirolimus (Torisel<sup>®</sup>)

(SMC), the equivalent to NICE for NHS Scotland, has approved the use of axitinib as second-line treatment for advanced RCC after the failure of immunotherapy or sunitinib<sup>29</sup>. It is hoped that NICE will approve axitinib in 2014.

Another group of protein kinase inhibitors, called mTOR inhibitors, such as **temsirolimus (Torisel<sup>®</sup>)** and **everolimus (Afinitor<sup>®</sup>)**, act in a similar manner to TKIs by interfering with the signalling pathway that controls tumour cell growth and angiogenesis. Temsirolimus is given through a drip in a vein in the arm over 30-60 minutes once a week for as long as it is working. Everolimus is a tablet that 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<sup>23-25</sup>.

In the UK, temsirolimus can be used to treat patients with a poor outlook (prognosis) and everolimus is used as second-line treatment after sunitinib or pazopanib has stopped working or isn't tolerated<sup>12</sup>. Both temsirolimus and everolimus are licensed for the treatment of advanced kidney cancer in the UK, however they have not been recommended by NICE and are therefore not available in NHS hospitals because they are considered to be too expensive. However, you may have treatment with mTOR inhibitors as part of a clinical trial or through a government funding scheme, such as the Cancer Drugs Fund.

You can find more information about targeted therapies on the Cancer Research UK website [www.cancerresearchuk.org](http://www.cancerresearchuk.org) (see page 34).

## MONOCLONAL ANTIBODIES

**Bevacizumab (Avastin<sup>®</sup>)** 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 targeted therapies, 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, tiredness, 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 clinical nurse specialist (specialist nurse) or doctor about your side effects and any other medicines you are taking.

## Other treatments

### RADIOTHERAPY

**Radiotherapy** uses high energy X-rays to destroy cancer cells. For patients who are unable to have surgery, 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, or for the treatment of cancer that has come back (recurred)<sup>12</sup>.

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**)<sup>12</sup>.

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.

## 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?



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 few days 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** or **CyberKnife**) 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<sup>30</sup>. Stereotactic radiotherapy can now be used to treat metastases found in the liver, lung and pancreas, as well as the brain.

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.



## New treatments

Cancer researchers are always looking for new and more effective ways of treating kidney cancer, as well as trying to find out what causes cancer and how to prevent it. All treatments need to be rigorously tested before they are allowed onto the market to make sure they are safe, they are effective at treating cancer, and they work better than treatments that are already available. Testing new treatments is done in **clinical trials**. For more information about clinical trials, please take a look at the James Whale Fund for Kidney Cancer website or the Cancer Research UK website (see page 34).

The following new treatments are being investigated in clinical trials:

- Monoclonal antibodies, such as naptumomab, cG250, and nivolumab are being investigated alone or in combination with interferon or everolimus for the treatment of advanced kidney cancer or to reduce the risk of the cancer coming back after surgery
- New targeted therapies, such as AZD2014 (an mTOR inhibitor) and lapatinib (a TKI) are being tested for the treatment of advanced RCC. Targeted therapies are also being investigated to try to find the most effective way of taking these drugs
- New immunotherapy drugs, such as the anti-PD-L1 antibody, are being tested to see if they are effective and safe to use for the treatment of advanced kidney cancer
- Cancer vaccines are designed to stimulate the body's own immune system to fight cancer. Cancer researchers are studying 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.



# 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, such as: Shock and fear; sadness and anger; disbelief and 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 34.

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 can be a supportive and positive option when the cancer is no longer curable; it 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, complementary therapists and chaplains, or the service can be provided by a specialist nurse.

Palliative care teams help to manage your symptoms and enhance your feeling of wellbeing. There are a number of support services available to patients who are living with incurable cancer that can help to improve quality of life. For example, Marie Curie offer a range of complementary therapies that patients can access at their hospices for a few hours, or by attending a specific clinic. These therapies include acupuncture, aromatherapy, massage, reflexology, and shiatsu, which help patients relax and improve their feeling of wellbeing.

## 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 Macmillian nurse will also help you claim any benefits you are entitled to. A number of means tested and non-means tested benefits might be available, depending on your circumstances. 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 Cancer Research UK have some useful advice (see page 34).

## 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. James Whale Fund for Kidney Cancer has a dedicated telephone careline (0330 111 2 333), where you can talk to people who have experience of kidney cancer or you can join the patient and carer forum at [www.jameswhalefund.org](http://www.jameswhalefund.org). You could also call a Macmillan nurse on 0808 808 0000 or a Cancer Research UK 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 wellbeing.

You can find out if any of these therapies are available near you by contacting New Approaches to Cancer, a UK charity (see page 34).



## Where to Find More Information and Support

**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 0300 111 0143 (10am-4pm Mon-Fri) or visit [www.jameswhalefund.org](http://www.jameswhalefund.org)

**Kidney Cancer Careline** is a dedicated telephone helpline from the James Whale Fund for Kidney Cancer that provides support and encouragement to kidney cancer patients, their families and carers.

Call 0330 111 2 333 (10am-4pm Mon-Fri, 10am-6 pm Wed, 4-6pm Sat-Sun) or visit [www.kidneycancercare.org.uk](http://www.kidneycancercare.org.uk)

**Kidney Cancer Support Network** is a patient forum for the exchange of ideas and information between carers and patients throughout the UK.

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.html](http://www.kidneycancersupportnetwork.co.uk/Map.html)

**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)

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

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

**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)

**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.cancerresearchuk.org/cancer-help/](http://www.cancerresearchuk.org/cancer-help/)

**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)

**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)

**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)

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



## Further Reading

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## Glossary

### 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.

### ASSISTED ROBOTIC SURGERY

A type of keyhole (laparoscopic) surgery that uses a robot to help the surgeon.

### 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.

### CHROMOPHOBE RCC

A subtype of renal cell carcinoma, which accounts for 5% of RCC cases.

### CLEAR CELL RCC

The most common subtype of renal cell carcinoma, which accounts for 75% of RCC cases. The cancer cells appear clear under the microscope and have large nuclei.

### CLINICAL NURSE SPECIALIST (CNS)

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

### CLINICAL ONCOLOGIST

A doctor who specialises in radiotherapy treatment for cancer.

### CLINICAL TRIAL

A rigorously controlled research study that finds new ways to prevent, diagnose or treat disease. Clinical trials test new treatments in people with cancer to make sure they are safe and effective at treating cancer.

### COLLECTING DUCT CARCINOMA

A subtype of renal cell carcinoma, which develops in the cells that line the collecting ducts in the kidney cortex.

### 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.

### CYBERKNIFE (GAMMA KNIFE SURGERY, STEREOTACTIC RADIOSURGERY OR RADIOSURGERY)

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

### CYST

A closed sac which may contain air, fluids, or semi-solid material. Once formed, a cyst can 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.

### 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.

### FIRST-LINE TREATMENT

The first treatment given for a disease, often as part of a standard set of treatments. First-line treatment is usually the one accepted as the best treatment for the disease, and if it doesn't work or causes severe side effects, other treatments may be added or used instead.

### FRACTIONS

Daily radiotherapy treatments.

### FUHRMAN SYSTEM

A system used for grading renal cell cancer to indicate how quickly or slowly the cancer is likely to grow and spread.

### 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, RADIOSURGERY OR CYBERKNIFE)**

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.

#### **HAEMOPTYSIS**

Coughing-up blood.

#### **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.

#### **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.

#### **MEDICAL ONCOLOGIST**

A doctor who specialises in the medical treatment of cancer.

#### **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.

#### **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.

#### **PARTIAL NEPHRECTOMY OR KIDNEY/NEPHRON SPARING SURGERY**

Surgical removal of part of the kidney containing the tumour to keep as much normal kidney tissue as possible so that the remaining kidney is still able to work.

#### **PAPILLARY (OR CHROMOPHILIC) RCC**

A subtype of renal cell carcinoma, which accounts for about 10-15% of RCC cases. The tumours have characteristic papillae or nodules on the surface.

#### **PERCUTANEOUS**

A medical procedure carried out or occurring through the skin.

#### **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.

#### **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.

#### **RADICAL NEPHRECTOMY**

Removal of the whole kidney and surrounding fatty tissue, the adrenal gland, and nearby lymph nodes.

#### **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, GAMMA KNIFE SURGERY OR CYBERKNIFE)**

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 type of 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. RCC accounts for 90% of kidney cancers.

## **SECOND-LINE TREATMENT**

Treatment given when first-line treatment doesn't work, or stops working, or causes severe side effects.

## **SECONDARY CANCER**

Cancer that has spread to another part of the body from the place in which it started (primary cancer). Secondary cancers (tumours) are the same type

of cancer as the primary cancer. Also called secondaries or metastases.

## **STAGING**

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

## **STEREOTACTIC RADIOTHERAPY (OR RADIOSURGERY, GAMMA KNIFE SURGERY OR CYBERKNIFE)**

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

## **TARGETED THERAPY**

Biological therapies that block the action of certain enzymes, proteins or molecules involved in the growth and spread of cancer cells.

## **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.

## **TUBEROUS SCLEROSIS**

A genetic disorder characterised by abnormalities of the skin, brain, kidney and heart.

## **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.

## **URETER**

The thin tube or duct that carries urine from the kidney to the bladder, where it is stored. There are two ureters, one attached to each kidney.

## **UROLOGY AND UROLOGIST**

The study and treatment of the urinary tract in women and the urogenital system in men. An 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.

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Next review: 2016



## James Whale Fund for Kidney Cancer and Kidney Cancer Scotland

James Whale fund for Kidney Cancer 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.

Kidney Cancer Scotland is a Scottish division of James Whale fund for Kidney Cancer. It has been set up to address specific and local needs of Scottish patients and carers.

### 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, The Old Coach House, High Street, Harston, Cambs. CB22 7PZ**

Make a credit or debit payment (except Diners) on the phone, by calling **0300 111 0143**

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.*

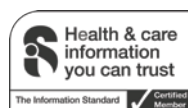


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