

Understanding Kidney Cancer

Surgery & Recovery

**A guide for kidney cancer patients
and carers across the UK**

Many people with kidney cancer continue to lead fulfilling lives.



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Your kidney surgery and recovery

This booklet contains information about:

- The routine checks you will have before surgery
- Types of surgery
- What to take into hospital
- What to expect while in hospital
- Some of the immediate physical and psychological after-effects of surgery
- Your longer-term physical and emotional recovery from surgery, as well as dealing with fatigue
- Questions you may want to ask your specialist team

This booklet aims to give general information that you may find useful before and after surgery. It is important to follow any specific advice given by your hospital and the material in this booklet.

Welcome

...to our 'Understanding Kidney Cancer Surgery & Recovery' booklet

To help the journey you are on, we have specifically designed this booklet for you to read at your leisure. We hope this booklet will help inform you and your loved ones when you need guidance and information about surgery and recovery. This provides easy to-understand scientific knowledge on kidney cancer, alongside practical information on living day-to-day with the disease and the range of emotions you may experience.

We understand that your experiences and treatments will be unique to you. We hope the information and insights provided in this booklet will help you make informed choices in all areas of your journey and help you find support if, and when, you require it.

If you require support or have any questions on any aspect of kidney cancer care please ring our **Careline** on **0800 002 9002**. In addition, we also run the following support services:

- Free Counselling service; please call **0300 102 1001** or **01223 870 008** to arrange a consultation
- We provide a closed Facebook group; find this by searching '**kcusupportgroup**' in Facebook
- We present free to attend 'Living with kidney cancer' days in locations across the country
- And there are a number of local support groups around the UK please call **01223 870 008** to find out more

We are '**here to listen, inform and support**'

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 ¹.

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, recover faster 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 ¹.

Cryotherapy (Cryoablation)

Cryotherapy can be used to treat early stage (stage T1a) kidney tumours that are less than four cm in size. Because it is less invasive than other surgical procedures for kidney cancer, it can be used on older patients who are not well enough to have surgery. It can also be used to treat multiple small kidney tumours, and tumours in both kidneys (bilateral disease), which can be found in patients with an inherited condition called von Hippel-Lindau syndrome. If you would like more information on Cryotherapy, you can find our Cryotherapy factsheet on our website.

Before going into hospital

Pre-assessment

Your overall health will be checked before you are given a general anaesthetic. You will usually be asked to attend a pre-assessment clinic before your surgery date. Sometimes this assessment takes place when you are in hospital for your operation. You will be asked several questions and have a physical assessment.

These questions are likely to be asked

- If you are taking any medication and at what dose
- Your GP's details and a relative or friend's contact information
- If you smoke (you may be asked to try to cut down, or stop smoking, to help your recovery from the anaesthetic and surgery)
- If you have any allergies

Admission to hospital

If any health conditions are highlighted by the pre-assessment you may need more tests. The time taken to do these may delay your surgery for a short while. Although you might feel anxious about any delay, it should not make a difference to the outcome of your treatment. In most cases after your kidney surgery you will still have one remaining functioning kidney, and maybe a portion of the kidney that has been operated on, which will continue to work.

Before your operation to remove your kidney tumour, you will undergo some tests to check the function of the kidneys. This will enable you to be offered the right level of support after the operation. Patients who are having both kidneys removed, or who have poor kidney function, are usually referred to a Consultant Nephrologist (medical doctors specialising in kidneys) before surgery, to talk about renal dialysis. Renal dialysis is the artificial cleansing of blood to replace the basic function of the kidney.

What to take with you

You may be given a list of essential items to bring into hospital with you. Whether you are given a list of items to bring or not, the following may be helpful if you are staying overnight in hospital.

Clothes

If possible, choose loose-fitting nightwear that is simple to put on and take off, and which allows easy access to your back, as a nurse will need to check your dressings after surgery. You may have temporary plastic tubing, called a drain, running from your tummy (where you had your surgery) into drainage bottles or bags. This may make longer nightwear awkward. Drains are put in place during the operation to collect any excess fluid that might build up around the wound. It may be helpful if you have a dressing gown with pockets so the drain can be put in the pocket.

The physical assessment may include

- Blood tests
- Electrocardiogram or ECG (a test that measures the electrical activity of the heart and detects any possible problems)
- Blood pressure
- Urine test
- Chest x-ray
- Screening for MRSA (a type of bacterial infection)
- Pulse
- Temperature

Normally you do not have to stay in your nightwear while in hospital; most people wear everyday clothes. As with nightwear, it is helpful to choose clothes that are loose, comfortable and easy to put on and take off. A pair of slippers, flip flops, or shoes may also be useful.

Toiletries

Take all your usual toiletries and a towel (sometimes these are provided). Wet wipes may also be useful. It is best to avoid using deodorant, talcum powder or body lotion immediately before surgery. It is also important not to apply these to the area where you have had surgery, until your wounds are fully-healed.

Money and valuables

Most hospitals have policies about taking money and valuables onto patient wards. In some hospitals, you will have access to a lockable bedside cabinet for small valuable items that only staff have access to. It is a good idea to check with the hospital before the operation. Generally, it is sensible to leave valuables such as jewellery at home. You will usually be able to leave a wedding ring on during your operation; it will be taped over before you have your surgery.

To use the bedside phone, TV or access the internet, there will be a cost dependent on the hospital. In many cases you will be able to use your mobile phone, but you may need to put it on silent and avoid using it if it could disturb other people.

Food and drink

You can usually take some of your own food and drinks into hospital with you. Drinks and snacks are also available in most hospital shops. Most special diets are catered for in hospitals, but let the ward staff know your needs. Sometimes visitors will be allowed to bring in takeaway or home-cooked food for you, but again discuss this with the ward staff first.



If you have not had any tests done in advance (see 'Pre-assessment'), they will be done once you have been admitted. The aim is to check that you are fit for surgery and for a general anaesthetic. Follow any instructions you are given, such as when you can last have something to eat or drink before the operation. You will usually be asked to remove any nail varnish and makeup before surgery. If there is anything you are unsure about, ask your doctor, ward nurse or urology nurse specialist.

It is common for the surgical team to use a marker pen to draw on your skin to mark the site of the operation. You might be given anti-embolism stockings (elasticated support stockings) to wear during, and for a short time after, your operation. They reduce the risk of harmful blood clots forming. Some people are given a series of injections after their operation to further reduce the risk of blood clots.

Your anaesthetist will also usually visit you on the ward before your surgery. If you are feeling anxious and would like something to relax you before the operation, this is the time to ask. If you are wearing any jewellery, the staff will discuss with you whether it can be secured with tape, or will need to be removed before the operation and possibly placed in the ward safe.

If you have false teeth you will probably need to remove these before going to the operating room. If you wear glasses or use a hearing aid, you may be able to wear these to the anaesthetic room, where you will be asked to remove them. It is a good idea to have these items clearly labelled with your full name.

You will be taken to the anaesthetic room where the theatre checklist will be carried out again, this time by the theatre staff. Next you will be given a combination of drugs (usually anaesthetic, pain relief and anti-sickness drugs) into a vein (intravenously) and oxygen to breathe through a face mask. You will usually be asked to take deep breaths and as the anaesthetic takes effect, you will fall into a deep sleep. Once you are fully-anaesthetised you will be taken into the theatre.

Before going into the operating theatre for your surgery, the nursing staff will check

- Your name band
- Whether you have any allergies
- When you last ate and drank
- That you have a theatre gown on
- Whether you have jewellery or body piercings
- That you are not wearing any nail varnish or make-up
- Whether you have any crowned or capped teeth
- Whether you are wearing contact lenses

Recovering from your surgery

If you work, you may wish to discuss returning to work with your occupational health or human resources department, or your manager. Many people are able to arrange a phased return to work, or to work part-time for a while, to help in managing their fatigue. You can get more information about coping with fatigue from your urology nurse specialist, or by calling our Kidney Cancer Careline: **0800 002 9002**.

Returning to normal activities

You will be advised not to lift or carry anything heavy until your wounds have fully healed. You should be able to return to most of your normal activities after six weeks of your operation, but this will vary from person to person. It can help to take things gently at first. You may have more discomfort and stiffness as you bend and move your back more, but this usually improves naturally over time.

Driving

Your specialist team will usually offer advice on when to return to driving. You need to feel comfortable and safe to do so, as well as being confident that you are able to drive normally. It is likely that you will be advised to not drive for a few weeks. You may also want to check with your insurance provider that you are covered.

Sexual activity

You can begin sexual activity whenever you feel comfortable. However, after kidney surgery the areas around where you were operated on, may continue to feel sore and your back may feel stiff for several weeks or longer.

Returning to work

When you return to work will depend on the type of job you have, the extent of your surgery and any additional treatments you will be having. Your urology nurse specialist or GP will be able to give you more specific advice. The team looking after you can give you a sick certificate for the time you are in hospital. Your GP can then supply you with any further sick certificates.



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Glossary

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.

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.

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 an 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 (Cryoablation)

Kills the cancer cells by freezing the tumour.

Cyberknife (gamma knife) 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.

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.

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.

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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.

Medical Oncologist

A doctor who specialises in the medical treatment of cancer.

Metastases or secondaries

Areas of cancer spread.

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.

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.

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.

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.

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).

Glossary

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.

Urology Specialist Nurse

Refers to Clinical Nurse Specialist.

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 grey. Air absorbs least, so lungs look black.

Help our cause

We receive no government funding and are dependent on raising money from other sources. Contributions made to Kidney Cancer Scotland will stay in that country. Please include Gift Aid to your donation. You can download the Gift Aid form from our website or contact us on **01223 870 008**.

If you would like to make a donation, you can do so in the following ways:

- 1 Make a donation online by visiting **www.kcuk.org.uk/donate/**
- 2 Send a cheque made payable to **'Kidney Cancer UK' or 'Kidney Cancer Scotland'** to:
Freepost KIDNEY CANCER UK (no need to add our postal address)
- 3 Send a donation to our bank account with your name as a reference
Kidney Cancer UK (Barclays)
Sort code 20-17-35 Account 80098094
Kidney Cancer Scotland (RBS)
Sort code 83-20-22 Account 11896991
- 4 Make a credit or debit payment (except Diners) on the phone, by calling **01223 870 008**.
- 5 Make a legacy. Please contact us about the best way to do this.

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

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Kidney Cancer UK and Kidney Cancer Scotland

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.

'Here to listen, inform & support'



This booklet was produced with the help of an unrestricted educational grant from Pfizer.



We are social



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Here to help

