

This book is written and produced by Kidney Cancer UK

# ***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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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.

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# Welcome

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

To help you understand kidney cancer and 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 **Support Line** 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 closed Facebook Groups; find these by searching '**kcuksupportgroup**' or '**kcukmetastaticgroup**' or '**kcuksurgerygroup**' or '**kidneycancerukcarersgroup**'
- We present free to attend 'Living with kidney cancer' days in locations across the country and webinars on Zoom
- Coffee, Cake & Chat online support sessions, to find out more visit **[www.kcuk.org.uk/coffee-cake-chat](http://www.kcuk.org.uk/coffee-cake-chat)**
- And there are a number of local support groups around the UK please call **01223 870 008** or visit **[www.kcuk.org.uk/patient-support-groups](http://www.kcuk.org.uk/patient-support-groups)** to find out more

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

# Types of kidney cancer surgery

## 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 whilst leaving as much normal tissue as possible. It means that some working kidney is left behind and is 'preserved'. For this reason, a partial nephrectomy may be performed for people who only have one kidney, who have pre-existing kidney disease or who have tumours in both kidneys. Specialist surgeons (urologists) now treat most early stage (stage 1) kidney tumours that are less than 7 cm in size with partial nephrectomy, if possible <sup>1</sup>.

## Radical Nephrectomy

During a radical nephrectomy the tumour bearing kidney tissue is removed completely. Usually this involves removal of the fatty tissue surrounding the kidney and sometimes the adrenal gland and nearby lymph nodes. However, the extent of a radical nephrectomy can vary between patients. You can live perfectly well with just one working kidney. If both kidneys are removed because of tumours in both kidneys (bilateral renal cell carcinoma), or because the kidneys do not work, you will need a form of renal replacement therapy such as life-long dialysis or a kidney transplant.

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

## Keyhole (Laparoscopic) and robotic surgery

The majority of radical surgery and partial nephrectomies are performed Laparoscopically. This will involve a referral to a specialist urological surgeon with particular experience in laparoscopic kidney surgery. Some specialist centres now use a robot to assist with this surgery.

## Your notes

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Laparoscopic nephrectomy is generally the operation of choice unless the surgeon believes that an open approach would be safer or more effective in your case. The operation is carried out using several small incisions or cuts in the skin of the tummy (abdomen), rather than one large incision. One incision is made slightly larger than the other in order to retrieve the kidney in one piece.

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<sup>1</sup>.

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.

Robot-assisted 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<sup>1</sup>. The size and position of the tumour in the kidney will determine if robotic surgery is an option.

### **Ablation (Cryotherapy and Radiofrequency ablation)**

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. You will require a general anesthetic. If you would like more information on Cryotherapy, you can find our Cryotherapy factsheet on our website.

### **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

## 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.

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 and abdomen, as a nurse will need to check your dressings after surgery. You may have a 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, you may wish to consider wearing a t-shirt and shorts combination instead of a nightie/pajamas.

## 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

Drains are sometimes 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 drainage bag / bottle can be put in the pocket.

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 closefitting 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.



# Admission to hospital

## Books, magazines and music

Some people like to bring something to read. Newspapers and magazines are also often available to purchase in a hospital shop and sometimes from a trolley service. You may also want to bring a device to listen to music or to watch a film. If you do, please take headphones so you do not disturb others.

## Medicines

Bring any medication you are taking into hospital with you. You should discuss any medicines, or herbal supplements, you are taking with your specialist team before you are admitted to hospital. Ask at pre-assessment which, if any, of your medications you should take on the morning of your operation. Some medications will need to be taken, while others are best taken after your surgery.

You may need to telephone the ward before going to the hospital to make sure there is a bed available. You should be given details of where to go and who to speak to on your arrival. If you still have questions about your operation, it is best to speak to your urology nurse specialist. If you are not able to do this for any reason, write your questions down and take them with you to ask your consultant on the day of your operation. Each ward has its own policy on visiting and how many people can visit at a time. You will need to check your hospital's visiting policy, with the ward staff, when you are admitted.

## Before surgery

You will usually be admitted to the hospital on the morning of your operation, or occasionally the day before. A doctor from the surgical team will talk to you about your operation and discuss what has been planned. This is a good time to ask questions and talk about any concerns you have. If you have not already signed a consent form, you will be asked for your written consent. This confirms that you understand the benefits and risks of your surgery, and what you are agreeing to. If you are unsure, do not be afraid to ask the doctor to explain further.

## Your notes

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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

# After surgery

Everyone reacts differently to surgery, but most people recover well with few major side-effects. The same goes for having an anaesthetic; some people wake up very quickly and others can feel very sleepy for several hours afterwards. While you are waking up from the anaesthetic you may be wearing an oxygen mask or nasal cannula (short, soft tipped tubes in the nostrils) to give you extra oxygen. You may have a blood pressure cuff on your arm and a small device clipped to your finger so your blood pressure, pulse and oxygen level in your blood can be checked. You may also be given fluids via an intravenous drip until you are able to drink normally. Although you might find this equipment restricting, you will usually only have it for a short time.

You will also have a urinary catheter inserted into your bladder through your waterpipe (urethra), which is used to collect urine. This will have been inserted during the operation whilst you are asleep to empty your bladder for you. After the operation, the amount of urine collected in a bag, via the catheter, will be measured over a period of time. This will allow the medical staff to check that your remaining kidney/s are producing urine after the operation. The catheter may drain bloodstained urine for a day or two, which is not unusual after this type of surgery. The tube will then be taken out once the urine clears. After the catheter is removed, the nursing staff will check that you can pass urine and empty your bladder normally. Occasionally it may be necessary to keep the catheter in for longer (maybe 10 days) to allow the bladder to heal. If you have had the kidney and ureter removed a cystogram will be performed to check the bladder and you may be required to have a small dose of Chemotherapy inserted into the bladder.

Following your surgery, and when you feel able, you can drink some water. The staff on the ward will advise you about this. It is best to start by taking a few sips and gradually drink more. Once you are drinking without any problems, you can then usually start eating. The nursing staff will check your wound/s and general health regularly. You will be encouraged to get out of bed and gently mobilise as soon after surgery as you feel able.



People can feel dizzy immediately after their operation because they may have lost some blood during the operation, or because their blood pressure is low, which can be a temporary side effect of the anaesthetic drugs as it wears off. The nursing staff will be able to advise you on whether you should call for help if you need to get out of bed and how far you should walk.

### Dealing with drains

Fluid can build up around the wound after the operation. You may have wound drains inserted during the operation. These are tubes that drain blood and bodily fluids from the wound into a bottle or small bag. You can walk around with the drains in. Drains are usually removed before you are discharged from hospital. However, some people are required to go home with their drains in and either return each day to have them checked and the content measured, or, in some hospitals, patients or their carers will be taught how to do this. These drains may stay in for a few days after surgery and will then be removed by a nurse.

Many hospitals across the UK, might send you home with a self-injection of blood thinning medication for 28 days to reduce the chance of blood clots. You will be provided information from the hospital on how to do this.

### Possible after-effects from surgery

After the operation you will be given an intravenous drip of fluid and salts until you can eat and drink normally. Tubes may be used to drain excess fluid from your wound to assist healing. These will usually 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>2</sup>.

Most people go home between one to five 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>2</sup>.

### Your notes

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# After surgery

A partial or radical nephrectomy is a major operation and, as with any operation, there can be some risks, such as infection, urine leaks and 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>1</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 receive a follow up outpatient appointment to check your recovery around six weeks after your surgery where your consultant will discuss with you your prognosis and/or treatment options and follow-up schedule. Some hospitals will refer to their oncology departments if research studies are open.

Listed below are some of the common after effects of surgery. Not everyone will have them, and they are usually temporary or able to be controlled. Talk to your specialist team or urology specialist nurse if you have any concerns about these.

## **Pain and discomfort**

You are likely to have some pain or discomfort after surgery, but everyone's experience is different. Deep breathing and coughing may be painful because the incision is close to the diaphragm. However, a physiotherapist will advise you on how to do breathing exercises after surgery and these will be important to prevent a chest infection. Following a laparoscopic (key-hole) operation, it is usual to have some mild shoulder or stomach pain for a couple of days. This pain is often described as 'wind-like' pain, and is due to the surgeon using gas to inflate your abdominal cavity so that he can see the kidney better during the operation.

## **Your notes**

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Many people experience pain, numbness and a burning sensation as a result of temporary damage to the minor nerves in the wound area. This should settle within the first few weeks or months after surgery. However, for a few people the pain continues. Contact your urology nurse specialist if you have continued concerns about your level of pain.

There are different types and strengths of pain relief available and they can be given as tablets, suppositories (waxy pellets placed into your back passage (rectum), or injections. What you are given will vary according to your needs.

Sometimes pain relief may be given via a device called a PCA (patient-controlled analgesia). This is a pump designed to give pain relief straight into your vein when you press a button. It is usually removed a day or two after surgery.

If you are in any pain while in hospital tell the ward staff, as you may need a stronger dose of pain relief, or a different type. If you do not feel your pain is controlled when you are back at home, contact your hospital team or GP.

**Nausea**

Not everyone will feel sick (nauseous) after surgery. Some people are more likely to do so than others, for example people having longer operations. Any sickness is usually only short term. Anti-sickness drugs (anti-emetics), given as a tablet or injection, can help to relieve nausea, so tell the nursing staff if you feel sick.

**Bruising and swelling**

There may be some purple bruising around the wound which spreads downwards with gravity and fades to a yellow colour. There may be some swelling of the surrounding skin, which your treatment team may call oedema. Bruising and swelling is a normal part of the healing process and should improve after a few days.

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# After surgery

## Wound infection

A wound infection can happen any time after surgery, until the wound is completely healed. It usually takes about two to three weeks for skin to heal and around six weeks for the internal stitches to dissolve. Contact your GP or urology specialist nurse straight away if you think you may have a wound infection. Any of the following symptoms could mean you have a wound infection:

- the wound feels tender, swollen or warm to touch
- redness in the area
- discharge from the wound
- feeling generally unwell with a raised temperature

If you have any of these symptoms you may need a course of antibiotics, which should stop the infection and discomfort.

## Change in sensation

Some people experience pins and needles, burning, numbness or darting sensations in the lower back area on the operated side. These symptoms are quite common and may go on for a few weeks or even months. These symptoms are usually temporary and improve with time, or completely disappear over a few months.

## Scars

Whatever surgery you have will leave some type of scar. Laparoscopic (keyhole) surgery will leave smaller scars. Looking at and feeling the scar for the first time can be difficult. Scar tissue is produced naturally by the body during healing. At first your scar will feel uneven to the touch and may feel tight and tender. Scars are often initially red, but will fade and become less obvious over time. You may wish to use a specialist skincare product to improve the appearance of scars, such as bio-oil, following consultation with your specialist nurse or consultant.

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# Recovering from your surgery

Recovery after surgery involves healing, both physically and emotionally, and the time this takes varies from person to person. Going home can bring mixed emotions. You may feel relief that the operation is over, but concern about needing to go back for your results. You may feel vulnerable because you no longer have the immediate support of the nurses, doctors and the hospital team. You will be given a contact number for the ward and urology specialist nurse, in case you want to talk through any issues. You can also call our Kidney Cancer's free Helpline on **0800 002 9002** or visit our website [www.kcuk.org.uk](http://www.kcuk.org.uk) for information and support. You can also join our closed facebook site, just search '**kidney cancer UK support group**' to 'talk' to people who have gone through similar experiences.

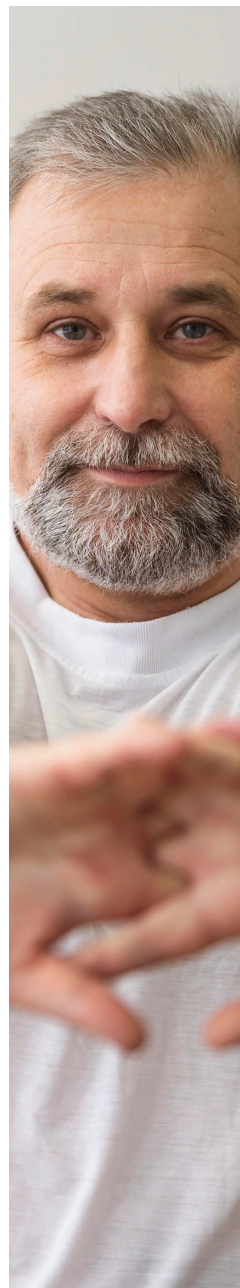
It is important you do not suffer in silence as there is help and support available for you from many dedicated sources and resources.

## Physical recovery

Once you get home from hospital, you should try to do a little more physical activity each day. Do not set yourself enormous tasks and remember to rest between them; your body needs time and energy to recover. Eating well will also help your body recover and your wound to heal. A healthy diet with foods you enjoy is best. Drink plenty of fluids and pass urine regularly; this will help to keep your remaining kidney healthy.

## Fatigue

Fatigue is different from normal tiredness: it is more extreme and unpredictable and is often not improved by a good night's sleep. Most people experience fatigue at some point during, or after, their treatment and it can last for weeks or even months. It can make a lot of difference to how you feel and how you cope with everyday life. Where possible, try to take things easy and do not be hard on yourself if you are unable to do as much as you used to. Pace yourself if you can; for example, by taking up offers of help and support with shopping, transport, childcare or housework. Gentle exercise can also help improve fatigue.



# Recovering from your surgery

You can get more information about coping with fatigue from your urology nurse specialist, or by calling our Kidney Cancer Support Line: **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.

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.





**Sport and leisure**

It can be useful to begin some gentle forms of exercise, such as walking, to help you maintain a good level of fitness. You may need to gradually build up the amount of exercise you do, as it is normal to feel tired after surgery. Before starting or re-starting any type of activity, it can help to get guidance from your specialist team or GP, and it is best to start slowly and with caution, particularly if the activity is new to you.

**Emotional recovery**

People will experience different emotions at different phases of their recovery. There is no right or wrong way to feel. Those around you may expect you to be well when you leave hospital, or once you are able to do most of the things you used to. However, there may be times when you feel you are struggling or on your own. This is common and there are people who can help and support you.

You can let your family know how you feel so they can support you. It can also help to discuss your feelings or worries with your specialist or urology nurse specialist. If you want to talk through your feelings in more depth over a period of time, your GP or specialist can usually arrange counselling or you can speak to our counsellor on **0300 102 0101**.



You might find it easier to share your feelings with someone who has had a similar experience to you. You can do this either one-to-one or in a support group. For more information on our individual support, or support group services in your area, call our free Kidney Cancer Support Line on **0800 002 9002**.



**Your notes**

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# Recovering from your surgery

## Leaving hospital

### When can you leave?

The length of your hospital stay will depend on what sort of operation you had, how you recover and the support available at home. Your specialist team will advise you on the amount of time you can expect to stay in hospital after your surgery. You will probably remain in the hospital for one to five days; generally open surgery takes longer to recover from than laparoscopic (keyhole) surgery.

The nurses on the ward may arrange for a district nurse to visit you at home whilst you are recovering, to care for wounds and drains.

You will be given a letter for your GP and you should have a week's supply of any medications you have been prescribed. Check before you are discharged who you should contact if you have any of the after-effects listed in this booklet, and make sure you have their contact details.

### Follow-up appointment

Before you leave hospital you may be given, or be told when to expect, an appointment to attend the outpatient clinic to discuss your pathology results after surgery. At this appointment, you will usually be told if further treatment is recommended. If you have not received this after 4 weeks then please contact your specialist nurse.

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## Questions you may want to ask your specialist team

- What will my scars look like?
- Will I have any drains and when will they be removed?
- How long will I need to stay in hospital?
- Who should I contact if I have a problem or concern?
- When will I get my pathology results?
- Can I have a bath or shower after the operation?
- Will I be able to pick up my children/grandchildren?
- When can I drive again?
- What household chores can I do when I go home?
- Is there anything I shouldn't do?
- When can I play sport or go to the gym again?
- Can I go away on holiday? Is it OK to fly? What about travel insurance?
- What support is available for people with kidney cancer in my area?

## Your notes

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# Recovering from your surgery

## Looking after your drains and wound

When you leave hospital follow any instructions you are given about caring for your wound. This will vary from hospital to hospital and depends on the kind of surgery you have.

If you have questions about caring for your wound, or what kind of follow-up care you will receive, contact your urology nurse specialist.

At some hospitals, and depending upon the type of surgery you have had, you may be discharged with a wound drain in place, and in others you are discharged once they have been removed. The amount of fluid your wound drains have collected, will be measured every day. When they are draining only a small amount, they will be removed. They are usually removed after about a week, even if they continue to drain, to reduce the risk of infection. If you are discharged with your drains still in place, they may be regularly checked at home by a nurse, or you may be asked to telephone or return to the hospital each day so that the drainage can be checked. This may sound frightening, but if your treatment team suggests it, they will give you all the information and support you need.

Some people find the removal of the drains a little uncomfortable; you may want to take some pain relief before this. The stitch (which holds the drain in place) is cut and removed and then the tube itself is taken out.

You are usually able to bathe and shower normally following surgery (if you have a waterproof dressing covering the wound), but it is advisable not to use any soaps or deodorant products on, or around, the area of your wound. The nursing staff on the ward will give you specific advice on caring for your wound and any dressings. They will also make any arrangements for the removal of your skin staples or stitches if they are not dissolvable. Your wound/s should heal within six to eight weeks. However, it may take several months for your lower back area to feel 'normal' again.

## Your notes

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**Care of your remaining Kidney if you have had your kidney removed**

Most people are able to function with one kidney instead of two, but tests will be done on a regular basis to check how well your remaining kidney/s is/are working. A urine test and blood pressure check should be carried out every year. Depending on the stage and grade of your kidney tumour, the hospital will arrange follow ups accordingly.

If you have one kidney you should avoid sports that involve higher risks of heavy contact or collision. This includes, but is not limited to, boxing, hockey, football, lacrosse, martial arts, football and wrestling. This may also include extreme activities such as skydiving. If you have a single kidney and decide to participate in these sports you should be extra careful and wear protective padding.

**Pathology results and check up**

You will see your surgeon usually two to approximately six weeks after surgery. This is to check on your recovery and give you your pathology results. You will be given the stage and grade of your tumour, and follow up will be based on something called the Leibowich score. Please see below for more details:

**Your notes**

Horizontal lines for taking notes.

# 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 and generally found in your pathology report <sup>4, 5</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:

**TX** main tumour cannot be measured

**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 fat around the kidney

**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





# Staging and grading kidney cancers

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 7 cm in size.

## Stage 2

The cancer is bigger than 7 cm 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.

## Your notes

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# Support and information

## Money matters

### Financial advice

Our benefits advisor, Mark Williams, can help you claim the benefits that are available to kidney cancer patients in the UK (except Northern Ireland, see below).

Mark is a survivor of kidney cancer. He was diagnosed in September 2019 and overcame the physical and psychological effects of the diagnosis. He has a wealth of experience of the benefits system, having spent 13 years in working age benefit departments in the Department for Work and Pensions. Mark holds a CIPD qualification.

### Mark offers the following expertise

A comprehensive understanding of Universal Credit and how it is calculated based on a patient's personal circumstances. Navigating your health journey in conjunction with Universal Credit and actions to take when a patient is diagnosed with a terminal illness.

### Advice regarding Personal Independence Payment (PIP)

Patients who live in Northern Ireland should consult: <https://www.nidirect.gov.uk/information-and-services/benefits-and-money/benefits-and-financial-support>

If you would like to ask our benefits advisor a question, please use the form on our website [www.kcuk.org.uk/benefits-advice](http://www.kcuk.org.uk/benefits-advice). Remember to include your contact details so that he, or a member of our team, can get back to you.

All telephone calls from Mark are, by default, recorded given the nature and subject of them. If you don't want your calls recorded, your questions can be answered via email.

A specialist nurse or health professional will be able to advise you about other grants that are available for you. These can be for mobility aids or to help with heating costs or household expenses related to your illness. A specialist nurse or health professional 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. 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?

### 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.

# Support and information

Kidney Cancer UK offers a dedicated free to call telephone **Support Line (0800 002 9002)**, where you can talk to one of our Health Professional nurses with experience of kidney cancer. If you leave a message out of hours someone will call you back. You can also apply to join our very popular closed Facebook groups by searching **'kcuksupportgroup'** or **'kcukmetastaticgroup'** or **'kcuksurgerygroup'** or **'kidneycancerukcarersgroup'**

You could also join a local support group if there is one in your area, call **01223 870 008** or visit **www.kcuk.org.uk/patient-support-groups/** to find out.

## Self-help

Regular exercise can help you feel better both physically and emotionally. Ask your doctor or nurse what kind of exercise would be suitable for you. Many people find that complimentary therapies, such as massage, aromatherapy, meditation or visualisation, can also lift the spirits, ease tension and restore a feeling of wellbeing. You could look at our website **www.kcuk.org.uk** under patient information where we have many free useful resources.

## Where to find more information and support

Kidney Cancer UK and Kidney Cancer Scotland are the UK's leading kidney cancer charities. We offer information and support to kidney cancer patients, their families and carers not only via a comprehensive website and closed facebook support group, but also regular online Coffee, Cake & Chat support groups.

We also assist with establishing local patient groups, bringing patients together to share their experiences.

Call Kidney Cancer UK **01223 870 008** (9am – 5pm Monday to Friday)  
Call Kidney Cancer Scotland **0141 428 3494** (9am – 5pm Monday to Friday)  
Or visit **www.kcuk.org.uk**

## Maggie's Centres

Maggie's offer free practical, emotional and social support to people with cancer and their families and friends.  
**www.maggiescentres.org**

## Macmillan Cancer Support

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

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

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# 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 follicling 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.

### **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.

# Glossary

## **Nephrectomy**

Surgical removal of a kidney. Either radical (the whole kidney and surrounding tissues) or partial.

## **Nephroureterectomy**

Removal of a kidney and the tube (ureter) that connects it to the bladder.

## **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).

### **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.

# Hospital appointments

<b>Date</b>	<b>Time</b>
<b>Location</b>	
<b>Notes</b>	

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# Your notes

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Edition 1.3

Last reviewed: April 2022

Next review: April 2023

## **Grateful to**

This booklet has been prepared with the assistance of Professor Grant Stewart and James Armitage, Consultant Urological Surgeon.

## **Edited by**

Susan Sireshuk, Kidney Cancer Health Professional Nurse and Lucy Willingale, Health Professional – lead. The Charity is appreciative to patients that also assisted in its review.

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# Your donation is essential to the work we carry out

We receive no government funding and are dependent on your donations whilst also raising money from other sources. How could you or someone you know help us and make a difference?

SET UP A MONTHLY DONATION

LEAVE US A GIFT IN YOUR WILL

ORGANISE A FUNDRAISING EVENT

TAKE PART IN ONE OF OUR CAMPAIGNS

VOLUNTEER

With your generous support we can continue to invest in patient support and research. Without research, the treatment patients receive today will be the treatment they receive tomorrow.

Please visit our website for more information about how you can support our work [www.kcuk.org.uk/support-us](http://www.kcuk.org.uk/support-us) or return the form below via Freepost by writing 'Freepost Kidney Cancer UK' on the envelope or ring **01223 870 008** where we will be happy to help you.



Name

Address

Town

Postcode

Email

Telephone

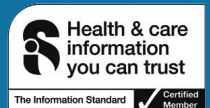
Please tell me more about

- Donating
- Making a gift in my will
- Volunteering
- Add me to your mailing list

# **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'**  
**[www.kcuk.org.uk](http://www.kcuk.org.uk)**



## **We are social**



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@KCScotland



Facebook.com/kidneycanceruk  
Facebook.com/KCScotland  
/groups/kcuksupportgroup



## **Here to help**

