Understanding Kickery Edicing Carcery & 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 'kcuksupportgroup' 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'

Types of kidney cancer surgery

Partial Nephrectomy Your notes 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 1. Radical Nephrectomy During a radical nephrectomy the tumour bearing kidney and the surrounding structures are removed. Usually this involves removal of the fatty tissue surrounding the kidney, 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 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 kidney and surrounding tissues are removed through this incision. Keyhole (Laparoscopic) and robotic surgery Sometimes, it is possible to use keyhole surgery (also known as laparoscopic nephrectomy) to remove the affected kidney. This will involve 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 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.



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.

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If you have not had any tests done in advance (see 'Preassessment'), 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 iewellery 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.

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.

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Your notes

Dealing with drains Your notes 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. Some people are able 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. 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 will 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 2. Most people go home between two 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 ². 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 1. 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.

After surgery

You should receive a follow up outpatient appointment to check your recovery between two to six weeks after your surgery where your consultant will discuss with you your prognosis and/or treatment options and follow-up schedule.	Your notes
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.	
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.	Your notes
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. Antisickness 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.	
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.	

After surgery

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 guite 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 a smaller scar. 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.

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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 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.

Your notes

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.



Sport and leisure Your notes 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 Careline on 0800 002 9002.

Recovering from your surgery

Leaving hospital	Your notes
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 two to ten 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.	

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?

You		

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.	Your notes
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 you may be discharged with your drains still 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.	

Care of your remaining Kidney if you have had Your notes 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, and kidney function tests should be checked every few years (or more often if abnormal results are found). 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 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, please see below for more details:

Staging and grading kidney cancers

has to o	ging is used to describe how big a cancer is and how far it already spread. Information from the tests and scans used diagnose your cancer is used to determine the stage of your ease.	Your notes
	TNM system is a common system used for staging nours ^{4,5} ;	
Т	(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 sizeT1b 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 sizeT2b is a tumour more than 10 cm in size	

Т3	the cancer has spread beyond the kidney to the tissues or organs around the kidney, for example a major vein or the adrenal gland	Your notes
	 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 	
Т4	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	
eg still	ur doctor will combine these figures to give an overall staging, T2 N0 M0, which means the cancer is bigger than 7 cm but confined to the kidney, there is no involvement of lymph des and there are no metastases.	

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;	Your notes
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.	

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 ^{5,6} :	Your notes
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.	

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 of 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 3.

Your	not	es	

Support and information

Support	Your notes
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?	
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. Kidney Cancer UK offers a dedicated free to call telephone careline (0800 002 9002), where you can talk to people 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 group by searching 'kcuksupportgroup'.	
You could also join a local support group if there is one in your area call 01223 870 008 to find out.	
0300 102 0101 KIDNEY CANCER COUNSELLING Here to support	

Support and information

Self-help Regular exercise can help you feel better both physically and emotionally. Ask your doctor or nurse what kind of exercise may be suitable for you. 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 could all look at our website www.kcuk.org.uk under 'patient information'. Where we have many free usual resources.	Your notes
Maggie's Centres Official site www.maggiescentres.org Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.	
Macmillan support www.macmillan.org.uk for a variety of support and information.	
Marie Curie Cancer Care 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/ kidnev 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 folliculing 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 been 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 slowing 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.

Glossary

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'



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Here to help



