Kidney Cancer

FACT SHEET

Consent Consultation General Information – Planning for Surgery and Beyond

Produced in association with





Consent Consultation General Information – Planning for Surgery and Beyond

This leaflet has been created to help you understand what is likely to happen following your consultation where the decision to have surgery to treat your kidney cancer has been made.

There will now be a period of waiting until the date of your operation, and during this time you may want to plan for the operation. It is common to find this period of waiting before the operation difficult emotionally. Your family and friends might also be worried about you, so it can be a difficult time for everyone. Be reassured that feeling like this is completely normal and some people find it helpful to keep busy and active doing things they enjoy. Seek more support if necessary from your medical team, family and friends and/or one of the charities listed below. As some point before the operation, you will be asked to have a pre-assessment to check you are healthy enough for the operation. The assessment is likely to include blood tests, ECG, blood pressure, urine test, pulse, and temperature. This is also an opportunity for you to discuss your treatment plan and raise any concerns you have with your medical team.

In addition to your medical team, there are a number of specialist charities who can support you and your loved ones with a range of services including support line, counselling, closed Facebook support groups, online & local support groups and other information relating to kidney cancer, and these include:

Kidney Cancer UK – www.kcuk.org.uk, Support Line (0800 002 9002), hello@kcuk.org.uk

Macmillan – www.macmillan.org.uk, Support Line (0808 808 0000)

Action Kidney Cancer – www.actionkidneycancer.org, Helpline (0800 121 8721), support@actionkidneycancer.org

Preparing for Admission

How will you get to the hospital for your operation? Do you need to make arrangements in advance such as asking a friend to drive you or make use of public transport? If you have mobility issues, ask if your hospital has any transport facilities which you can use.

What do you need to take with you? Has the hospital given you a list or do you need to compose your own/add to the hospital's list? Some things to consider; loose fitting nightwear, a dressing gown, toiletries, wet wipes, mobile phone, headphones and long charging cable/plug, medication, hairbrush/comb, toothbrush, toothpaste, slippers, something to read. Do you have a suitable small bag to hold what you need?

Do you need/want to take food/drink with you? Remember you will have limited storage space on the ward. Hospitals are required to take into account patient preference, religious and cultural backgrounds into account when providing food and drink in addition to their health needs, so if this is an issue for you, you may want to discuss your needs in advance with hospital staff.

Do you have anyone at home dependent upon you? You may need to make arrangements for any dependents to be cared for by someone else while you are in hospital and in the days or weeks afterwards. While many people may be able to manage with the support of relatives or friends, it may be necessary to seek more formal support if needed, such as local charities providing voluntary services short-term, paid care workers, or a short period in a residential home to recover.

Will you be able to manage financially? You might find that having your operation and weeks of recovery is a worry if you work and don't qualify for sufficient sick pay to cover your outgoings while you are off work. Check with your employer if you are entitled to sick pay and ensure that you can manage financially. Kidney Cancer UK can offer benefits advice if you need it. Benefits Advice - Kidney Cancer UK (kcuk.org.uk).

A healthy balanced diet will ensure your body is in the best possible condition to cope with the operation. Drink plenty of fluids (non-alcoholic) to keep the kidney(s) not being removed as healthy as possible. If you have other conditions which require a special diet your clinicians will give advice on the best diet for you to follow until your operation.

There is some evidence that being as fit as possible before your operation can aid recovery afterwards, as well as reduce stress levels. Making sensible changes to your exercise routine in the weeks leading up to your operation may help with your recovery but take care not to overdo things. Remember that a small amount of activity can make a big difference..

Preparing for Discharge

Assuming the operation goes well you may be discharged as soon as within the first 48 hours after your surgery, so planning ahead for your discharge can help.

What arrangements will you need to travel home? You will need to organise to be picked up and taken home. This might be a friend or relative, a taxi, public or hospital transport. You may still be in pain and walking any distance may be difficult. Ensure that you have a pillow available to put against your scar(s) so the car's seatbelt doesn't cause pain by pressing on your wound(s). Ensure the driver is aware that every bump can be painful so a smooth ride wherever possible will help you get home with as little discomfort as possible.

Are there any home aids which could help you in the first few days when you get home? A wedge pillow will help you as lying flat to sleep is difficult initially, or use of an electric bed can be helpful if available. A raised toilet seat will reduce discomfort, as will a sit and rise chair. If you think you could make use of any of these or other ideas, you may want to make arrangements in the weeks prior to going into hospital, especially if sourcing large items of furniture which may involve a wait for delivery. If you don't want to buy new items, try a charity shop which might have secondhand items, or online sites like eBay. You won't even necessarily need to buy aids – perhaps you can borrow from a relative or friend?

If support at home after discharge is likely to be an issue, try to organize meals in advance that can be left in your home ready for your return, so you don't have to worry about shopping for a few days. This may include pre-cooked, frozen meal-sized portions or a selection of ready meals and non-perishable food and drink items.

Preparing for the first 6-8 weeks of your Recovery from Surgery

Paracetamol is a good painkiller and kind to kidneys, so it would be useful to ensure that you have some at home in case you need them during your recovery. Your clinical team will advise you about use of ibuprofen-based pain relief which can be bad for kidneys if the kidney function is reduced, and codeine-based pain relief can cause/exacerbate constipation.

There is no specific diet that is suitable for kidney cancer patients. Your diet will depend on the presence of co-morbidities, such as diabetes, chronic kidney disease and chronic heart disease. If necessary, discuss your diet with your GP who can refer you to a registered dietitian. A diet for kidney disease is not likely to be suitable for you unless you have also been diagnosed with kidney disease.

Try to eat a healthy, well-balanced diet:

- one third of a healthy diet should be fruit and vegetables,
- one third carbohydrates, such as bread, rice, potatoes, pasta and other starchy foods,
- the remaining third should be composed of milk and dairy foods, meat, fish, eggs, beans, and
- a small proportion of foods high in fat and/or sugar.
- limit salt intake can also help your kidney(s).

Alcohol consumption in moderation is generally allowed after the removal of a kidney (or part of a kidney). The government's recommended maximum intake of alcohol is 14 units per week spread across 3 days or more for both men and women. However, avoiding alcohol intake during your initial 6-week post-surgery recovery makes sense so that your remaining kidney(s) is/are not over-stressed.

On the day of the Operation

A member of the surgical team and your anaesthetist will talk you through what has been planned after you have arrived at the hospital. It is important to ask any questions or concerns you may have, , so that you understand what is going to happen during the surgery. They will also ask you to give your written consent to having the operation. A marker pen may be used to mark the site of the operation and you might be asked to wear stockings to reduce the risk of blood clots forming. You will be asked to change into a hospital gown and told what to do with any personal items such as glasses, false teeth and hearing aids. You will be asked to wear tight stockings to help reduce the risk of blood clots while you are immobile.

Once in the anaesthetic room, a cannula will be inserted into a vein and you will be given drugs intravenously which will make you fall asleep. You may well be anxious, which is perfectly normal, and the medical staff will be there to reassure and support you.

After the operation is over you will wake up with monitoring equipment around you, a catheter to monitor urine production and a drain in your tummy. You may be given a pump which provides you with pain relief when you press a button. The nursing staff will check your wound(s) and advise you when to start drinking and eating. If you have mucus in your chest, you will be encouraged to hold a pillow against your wound(s) and try to cough the mucus up. You may feel nausea from the anaesthetic, this can be helped by medication which the nursing staff can give you. As soon as you are able to you will be encouraged to get up and move about gently.

Before Leaving Hospital

If there are no complications you should be able to go home within 48 hours of the operation. Before you leave hospital, the drains, catheter and pump are likely to be removed. Oral pain relief will be provided after the withdrawal of the pump, and you may need blood thinning injections in the first month or so after surgery to reduce the risk of blood clots. A member of the clinical team will show you how to administer blood thinning injections yourself at home for the first month or so after discharge, although a relative can be shown how to do this if you find it difficult.

Discharge

Before being discharged you will be given information about wound care and advised about arrangements for having stitches removed if necessary. You may be given pain relief to take home with you. Don't forget to pack all the belongings you brought into hospital with you, including any medication. If you are not yet able to walk through the hospital, wheelchairs will be available in the hospital to help you. Have a pillow ready to put against your wound site(s) to protect it/them from a car seatbelt. As the journey home might be a little uncomfortable, ensure that pain relief is topped up before leaving hospital.

Recovery

In the first few days after being discharged you will still be feeling sore and have difficulty walking. You may feel relieved to be home but tired from the operation and the effects of the anesthetic might not have entirely worn off. In addition to your wound(s), may still have pain in the shoulder from gas used during the operation. You may also not be able to move your bowels after the operation. These issues should resolve themselves over the first few days at home. Rest as much as you can and slowly build up with short periods of gentle movement. This will help your bowels to

start moving and dissipate the gas. In the meantime, taking painkiller can provide some relief. You might feel tired, upset and/or emotional during the days or weeks ahead – this is perfectly normal and will lessen as your recovery continues.

Note that Codeine based painkillers can cause constipation so are best avoided if possible. Your medical team will advise you about the safety of Ibuprofen based medication in your case, paracetamol is the best painkiller for those with reduced kidney function. The hospital will discharge you with suitable pain relief medication.

Swelling and bruising around your wound(s) will continue for a few days or weeks although you may feel aches and pains in this area for much longer, it is common to experience numbness and burning sensations after this type of operation. If you have any concerns during your recovery, please get in touch with your CNS or key worker for advice. If you have any symptoms of an infection (fever, feeling generally unwell) or a wound infection (redness, pain, swelling and oozing from the wound(s)), please contact your surgery or the ward where you were treated as soon as possible.

Patients who have had all or part of a kidney removed may be at higher risk of reduced kidney function, either temporarily in the months following their nephrectomy, or permanently if the remaining kidney(s) is/are not able to filter effectively. Because of this, nephrectomy patients will be regularly monitored and if necessary, referred to a nephrologist. This will be guided by your urologist or GP.

Try to do a little more physical activity each day and remember to rest in between. Eating a balanced diet will help you recover and your wound(s) to heal. Drink plenty of non-alcoholic fluids so that you pass urine regularly to keep your remaining kidney(s) healthy. Be careful of your wound(s) as you recover — avoid suddenly increasing your activity level, and activities that put stress on wound(s). Putting too much stress on your wound(s) can make recovery more difficult and cause complications, such as hernias. If your level of pain increases, this may be a sign that you have overdone things and should allow your body to rest for a while.

External wounds should be fully healed by 6 weeks but internally it takes much longer. The length of recovery will depend on the type of operation you have had as well as any other conditions you have which may affect healing and can take as long as a year to fully heal, so even after the visible wound(s) have healed, , you may experience twinges and numbness at times as your body recovers on the inside. Pain will gradually reduce to a low/manageable level within the first month or so but if pain doesn't reduce, or rises again, raise your concerns with your medical team.

You should check with your motor insurance company when you can resume driving as they may not insure drivers for a number of weeks after surgery. You need to have stopped any painkillers that have sedative effects and be able to freely perform an emergency stop. Practice the basic movements when the car is stationary and if you feel pain or soreness, don't drive, and try again in a few days.

There are no set rules about resuming sexual activity other than when it feels OK for you and your partner.

Fatigue is experienced by a lot of patients, and it can last weeks or months. Try not to be hard on yourself – take things easy and pace yourself. Don't be afraid to ask those around you for support with daily tasks until you feel you have more energy. Some people find that gentle exercise helps to reduce fatigue.

Follow-Up Appointment

At about 6-8 weeks after your nephrectomy, you will have a follow-up appointment with a member of your medical team to check that your wound(s) have healed, tell you the results of the tumour histopathology and advise you about follow-up monitoring and/or treatment recommended.

Glossary

Anaesthetist - A specialist in anaesthetics, pain management and intensive care

Cannula - A thin tube inserted into a vein to administer medication

Catheter - A thin tube inserted into the urethra to remove urine

ccRCC - Clear Cell Renal Cell Carcinoma, the most common type (75%) of kidney

cancers

Chromophobe - 5% of renal cancers are Chromophobe

Drains - A tube to drain liquids away from wounds

ECG - Electrocardiogram, measures electrical activity in the heart

Hernia - An internal part of the body pushes through a weakness in the surrounding

tissue wall

Hiistology - Study of the anatomy of tissues

Histopathology - Analysis of changes in body tissues caused by disease

Nephrectomy - An operation to remove all or part of a kidney

Nephrologist - A specialist in the study of kidneys

Papillary - 15% of kidney cancers are papillary renal cancer

Pathology - Study of the causes and effects of disease

Pump - Also known as a syringe driver, administers drugs under the skin to reduce

pain

RCC - Renal Cell Carcinoma, also known as kidney cancer, there are several types

Tumour - Abnormal growth of tissues which might or might not be cancerous

Recovery Tracker

This outline tracker from the <u>Royal College of Surgeons of England</u> will guide you in your recovery if you have no complications after your surgery, but we are all different and if you take slightly longer to get through your recovery you should not be concerned. Any complications from surgery or other health conditions are likely to result in a slightly longer recovery time. Discuss any concerns with your consultant at the 6-week checkup appointment.

Time after Op	Feelings	Activities	Traffic Light	Fit to work?
1-2 Days	Still in hospital, pain controlled by medication, difficulty moving about	Getting up and dressed, eat and drink normally. You may need a rest during the day		NO
3-7 days	Pain easing off slowly, movement easier, still get tired easily	As days 1-2 plus short (no more than 10 minutes) then rest		NO
1-2 weeks	Pain less and energy slowly returning	Increase activities in the house. Longer and more frequent walks resting after each walk		NO
2-4 weeks	Feeling stronger each day, less pain and more energy	Continue building activity, less need for rests during the day		Possibly, reduced hours and light duties.
4-6 weeks	Back to full range of activities, may still have fatigue and need occasional rest	Discuss returning to work with your employer		Yes

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Kidney Cancer UK

01223 870 008 Monday – Friday 9-5pm www.kcuk.org.uk



A dedicated free telephone Support Line that provides support and encouragement to kidney cancer patients, their families and carers. The UK's first dedicated kidney cancer counselling service. Visit our website and search 'counselling' or call our free counselling service.

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:

- Make a donation online by visiting www.kcuk.org.uk/donate/
- 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

- 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.