

FACT SHEET Post Nephrectomy & Follow Up

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1 - www.kcuk.org.uk

Returning to Normal Activities

You should be able to return to most of your normal activities about six weeks after your operation Recovery time does vary although you may still have some discomfort and stiffness when moving which should improve over time.

Returning to Work

You may have already returned to work in the last week or so or be planning to do so very soon. Getting back to your normal routine helps with your recovery. When you return to work will depend on the type of job you do, the extent of your surgery and any additional treatments you might need (if needed these will have been explained to you during your follow-up appointment). Those with physically demanding jobs will not be able to return to work as quickly as those with a job that is not physically demanding. While you may be keen to return to your normal work pattern, you may find it more tiring than you expect when you first return to work. You may wish to discuss your plans for returning to work with your employer. Some employers offer a phased return to work to help you ease back in and manage any fatigue you are experiencing, so it might be useful to discuss with your employer what accommodations they can make.

Follow-up Scans

During your follow-up appointment you will have been told about the schedule of monitoring scans if needed which will be put in place once your cancer diagnosis has been confirmed. The timing of the scans It will be based on your risk of recurrence (which will be assessed following the results of your tumour's pathology) as well as the guidelines being followed in your hospital. Type of scan and frequency may vary depending on the guidelines being used and it will be useful for you to understand what to expect in the years ahead assuming that your scans remain clear. Many patients experience anxiety and worry about these appointments, sometimes referred to as "Scanxiety", as the regular follow-up scans remind patients of their feelings/experience at the time of their original diagnosis. Over time these feelings may reduce as scan results continue to show no recurrence, but many patients find they never completely go away.

Blood Tests

Most scans will use contrast dye to show up parts of the body not always clearly seen, like blood vessels, and kidneys. As this dye can be harmful to the kidneys, radiologists will want to check that your remaining kidney(s) can cope. You may be asked to organise a blood test to check your kidney function about a month before each scan.

You may be asked to get the blood test done via your GP surgery, or in the hospital. The results from your blood test will be available electronically for the hospital radiologists, you won't need to have a copy of your results with you.

Kidney Function

Kidney function is measured via a blood test measurement called estimated glomerular filtration rate (eGFR measured in ml/min,). eGFR for someone with 2 kidneys is considered normal above 90ml/min. However, after a kidney (or part of a kidney) has been removed, the remaining kidney can swell to take over the work of the missing one so it can be difficult to predict what your expected kidney function will be. In general clinicians will be more interested in the trend over time and will want to check that your kidney function is stable (that the eGFR is not decreasing).. If your kidney function declines or is unstable, you may be referred to a kidney function specialist (nephrologist). Your kidney function will be monitored regularly by your GP surgery and/or hospital medical team. As blood pressure is affected by your kidney function, your blood pressure will also be checked regularly. Patients who have had a nephrectomy 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, patients who have undergone nephrectomy will be regularly monitored and if necessary, referred to a nephrologist.

Nutrition

There is no specific diet that is suitable for all 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 any concerns with your GP who can refer you to a registered dietitian if you need extra support. Most kidney cancer patients will not be diagnosed with kidney disease, so a diet specifically designed for people with kidney disease may not be appropriate.

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),
- 6-8 glasses of fluids including water, lower-fat milk and sugar free drinks.

More information can be found at The Eatwell Guide - NHS (www.nhs.uk)

Alcohol consumption in moderation is generally allowed after the removal of a kidney (or part of a kidney). Government guidance on maximum alcohol consumption is the same as for the general population - 14 units per week spread over 3 days or more for both men and women.

Exercise

Adults should do some type of physical activity every day. Exercise just once or twice a week can reduce the risk of heart disease or stroke. All physical activity is beneficial, even 10 minutes of walking every day, so you may want to incorporate this into your daily routine.

Following recovery from surgery you should aim to undertake at least 30 minutes of moderate activity for five days of the week. Moderate activity includes some of the actions involved in daily life, such as walking or cycling. It can make you feel warmer or even sweaty if it is a hot day. Exercise can make you feel better because of the released feel-good hormones (endorphins) that are release in the body when we exercise.

More information can be found at Exercise - NHS (www.nhs.uk).

Travel

Once you feel well enough you may want to have a holiday to help your recovery. If you plan to go abroad and don't have travel insurance, or if you take out a policy that excludes any cancer related issues, then the potential costs to you could be extremely high, especially if you subsequently need to be repatriated on medical grounds.

If you have been diagnosed with kidney cancer before you take out travel insurance, it will be assessed as a pre-existing condition. If you already had travel insurance before your diagnosis, check whether your policy covers your diagnosis. In general, travel insurance costs reduce over time, so if you were recently diagnosed it will cost more, and after 5 years clear of cancer the costs will be much less. Do ensure you disclose all health conditions to ensure that your insurance gives you all the cover you might need.

The Global Health Insurance Card (GHIC) has replaced the EHIC to cover free or discounted medical care in European Union countries and should be carried in addition to travel insurance, not instead of.

Kidney Cancer UK has compiled a list of insurance companies recommended by patients and their families which might help you <u>Travel Insurance and Kidney Cancer - Kidney Cancer UK (kcuk.org.uk)</u>. This list is only a guide so you are advised to do your own research to find the best travel insurance for you.

Adjuvant Treatment

Adjuvant (preventative) treatments are sometimes used after kidney cancer surgery to reduce the risk of the cancer returning. Adjuvant treatment may have been offered to you if your risk of recurrence is intermediate or high. Your consultant will give you further information about the treatment being offered to help you decide whether this treatment is right for you.

Moving on after your treatment

Diagnosis with kidney cancer and surgery is a very stressful experience. It is common to find it difficult to come to terms with your experiences. This will affect everyone differently – there is no right or wrong way to feel. After all the stress and activity of the last few weeks or months you may feel deserted – you don't have regular contact with your medical team anymore, you no longer have detectable cancer, but you still have that niggle at the back of your mind asking yourself "will my cancer return?". You may feel that your diagnosis was cathartic, and you want to make lifestyle changes. Or you may just want to return to your life as it was before your diagnosis. Family and friends might think you are "back to normal" and not realise that for you it isn't quite that simple.

However you feel, it can be difficult to move on after such a shocking experience but it is perfectly normal to feel like this.

If you think that you would benefit from support of various kinds, charities such as Kidney Cancer UK can offer you a range of support such as regular online support groups facilitated by health professionals, closed Facebook groups where you can virtually meet other people who have had similar experiences, a Support Line, benefits advice, free counselling, as well as more information about these services and other information on their websites.

Kidney Cancer UK – <u>www.kcuk.org.uk</u> Support Line (0800 002 9002) Email - <u>hello@kcuk.org.uk</u> Macmillan – <u>www.macmillan.org.uk</u> Support Line (0808 808 0000) Action Kidney Cancer – <u>www.actionkidneycancer.org</u> Helpline (0800 121 8721) Email - <u>support@actionkidneycancer.org</u>

Glossary		
Adjuvant	-	Preventative drug treatment given to help reduce the likelihood of
		recurrence
ccRCC	-	Clear Cell Renal Cell Carcinoma, the most common type (75%) of
		kidney cancers
Chromophobe	-	5% of renal cancers are Chromophobe
CKD	-	Chronic Kidney Disease
Contrast	-	A form of dye injected into the body to enhance the image of body
		tissues on scans
Creatinine	-	A chemical made and used within the body's muscles
eGFR	-	A calculation of kidney function based on age, gender and creatinine
		levels
Histology	-	Study of the anatomy of tissues
Histopathology	-	Analysis of changes in body tissues caused by disease
Leibovich Score	-	A way of measuring the risk of recurrence for Clear Cell Kidney Cancer,
		1-2 is low risk, 3-5 intermediate risk, 6 and over high risk
Nephrologist	-	Specialist in the study of kidneys
Papillary renal cancer	-	15% of kidney cancers are papillary renal cancer
Pathology	-	Study of the causes and effects of disease
Venuss Score	-	A way of measuring the risk of recurrence for Papillary Kidney Cancer,
		0-2 is low risk, intermediate risk 3-5, high risk 6 and over

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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:

- 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)
- 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.