Living with and beyond kidney cancer

Follow up after surgery for your kidney cancer
This leaflet is designed to give you information on what to expect following your surgical treatment for kidney cancer at the Royal Free London. It will hopefully help to inform you of the available support that you may find helpful during your recovery from cancer treatment.

**What can I expect after my treatment?**

Initially following your surgery you will need a period of time to recover fully before returning to normal activities. You should be active within your home and build up to returning to your usual tasks.

You may have some pain associated with the surgery and it is also common to feel lethargic after major surgery. You may need to rest or sleep more than usual in the first two weeks after the operation.

**The surgery results**

There are different types of cancer cells. The most common type of renal cancer cells are clear cell renal cancer. Less common types are papillary, chromophobe and collecting duct renal cancer. In the clinic today the surgeon will have explained the histology results to you. This refers to the grading of the cancer cells when examined under the microscope.

<table>
<thead>
<tr>
<th>Your histology results following surgery</th>
<th>please ask your doctor or nurse to complete:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of cancer</td>
<td></td>
</tr>
<tr>
<td>Staging</td>
<td></td>
</tr>
<tr>
<td>Risk group: Using a combination of factors the doctors can place patients in a risk group for the cancer returning after surgery</td>
<td></td>
</tr>
</tbody>
</table>

**When and where will I have my appointments?**

The specialist centre has been created to lead and coordinate the care of people with kidney cancer across north central London, north east London and west Essex. Following your surgery at the Royal Free London patients in the low and intermediate risk group would normally have all there follow up appointments back at your local hospital.

<table>
<thead>
<tr>
<th>Following your treatment at the Royal Free London your follow will take place at your local hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Hospital</td>
</tr>
<tr>
<td>Contact no.</td>
</tr>
</tbody>
</table>

**How often will I have my appointments?**

Many patients have their cancer successfully treated with surgery but there may be a chance of it coming back. One of the aims of your follow up appointment is to check for any sign of this. This stage and grading of the kidney cancer following your surgical treatment will help to identify which risk category applies to you. The risk of any cancer cells returning during your live time can be categorised into three main risk groups, low, intermediate and high risk.

<table>
<thead>
<tr>
<th>Tick</th>
<th>Risk of any cancer cells returning</th>
<th>Please ask the doctor or nurse to highlight your risk category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low risk</td>
<td>1. CT scan at six months post-surgery then, 2. Ultrasound scan and chest x-ray every 6 months up to 2 years post-surgery 3. Ultrasound scan and chest x-ray every year until 5 years post-surgery</td>
<td></td>
</tr>
<tr>
<td>Intermediate risk</td>
<td>1. Ct scan every six months until 2 years post-surgery then, 2. Ultrasound scan and chest x-ray every year until 5-10 years post surgery</td>
<td></td>
</tr>
<tr>
<td>High risk</td>
<td>1. Ct scan at three-six months post-surgery 2. Ct scan every six months until 5 years post-surgery then, 3. Yearly scan Ct or ultrasound until 10 years post-surgery</td>
<td></td>
</tr>
</tbody>
</table>

Your doctor may alter your follow up scan to meet your individual needs.

Please contact your local hospital if you have not received an appointment for your planned follow up.
This leaflet is designed to give you information on what to expect following your surgical treatment for kidney cancer at the Royal Free London. It will hopefully help to inform you of the available support that you may find helpful during your recovery from cancer treatment.

**What can I expect after my treatment?**

Initially following your surgery you will need a period of time to recover fully before returning to normal activities. You should be active within your home and build up to returning to your usual tasks.

You may have some pain associated with the surgery and it is also common to feel lethargic after major surgery. You may need to rest or sleep more than usual in the first two weeks after the operation.

**The surgery results**

There are different types of cancer cells. The most common type of renal cancer cells are clear cell renal cancer. Less common types are papillary, chromophobe and collecting duct renal cancer. In the clinic today the surgeon will have explained the histology results to you. This refers to the grading of the cancer cells when examined under the microscope.

<table>
<thead>
<tr>
<th>Your histology results following surgery</th>
<th>please ask your doctor or nurse to complete:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of cancer</td>
<td></td>
</tr>
<tr>
<td>Staging</td>
<td></td>
</tr>
<tr>
<td>Risk group: Using a combination of factors the doctors can place patients in a risk group for the cancer returning after surgery</td>
<td></td>
</tr>
</tbody>
</table>

**When and where will I have my appointments?**

The specialist centre has been created to lead and coordinate the care of people with kidney cancer across north central London, north east London and west Essex. Following your surgery at the Royal Free London patients in the low and intermediate risk group would normally have all there follow up appointments back at your local hospital.

**Following your treatment at the Royal free London your follow will take place at your local hospital**

<table>
<thead>
<tr>
<th>Name of Hospital</th>
<th>Clinical Nurse Specialist Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Contact no.</th>
<th>Consultant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**How often will I have my appointments?**

Many patients have their cancer successfully treated with surgery but there may be a chance of it coming back. One of the aims of your follow up appointment is to check for any sign of this. This stage and grading of the kidney cancer following your surgical treatment will help to identify which risk category applies to you. The risk of any cancer cells returning during your live time can be categorised into three main risk groups, low, intermediate and high risk.

<table>
<thead>
<tr>
<th>Risk of any cancer cells returning</th>
<th>Please ask the doctor or nurse to highlight your risk category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low risk</td>
<td>1. CT scan at six months post-surgery then,</td>
</tr>
<tr>
<td></td>
<td>2. Ultrasound scan and chest x-ray every 6 months up to 2 years post-surgery</td>
</tr>
<tr>
<td></td>
<td>3. Ultrasound scan and chest x-ray every year until 5 years post-surgery</td>
</tr>
<tr>
<td>Intermediate risk</td>
<td>1. Ct scan every six months until 2 years post-surgery then,</td>
</tr>
<tr>
<td></td>
<td>2. Ultrasound scan and chest x-ray every year until 5-10 years post-surgery</td>
</tr>
<tr>
<td>High risk</td>
<td>1. Ct scan at three-six months post-surgery</td>
</tr>
<tr>
<td></td>
<td>2. Ct scan every six months until 5 years post-surgery then,</td>
</tr>
<tr>
<td></td>
<td>3. Yearly scan Ct or ultrasound until 10 years post-surgery</td>
</tr>
</tbody>
</table>

Your doctor may alter your follow up scan to meet your individual needs.

Please contact your local hospital if you have not received an appointment for your planned follow up.
**What else should I look out for in relation to my kidney cancer?**

You should contact your GP if you:

- See any blood in your urine
- On-going pain at the wound site not relieved by painkillers

**Treatment summary**

These summaries the treatment received, from diagnosis through to the end of the treatment. They provide details of diagnosis, treatment and results following surgery and possible symptoms that may occur in the future.

These have been developed to help ensure that GPs are able to best support individuals in the community and to provide important information they may need in other healthcare settings.

A treatment summary will be given to all patients following surgical treatment or sent in the post shortly afterwards.

**Your key worker**

All patients diagnosed with a cancer will have a key worker who is usually the clinical nurse specialist (CNS). Your key worker will:

- Support you and your family at all stages during your illness
- Provide verbal and written information about your condition and treatment
- Co-ordinate your care
- Provide health education

Your key worker will now be the clinical nurse specialist at your local hospital to ensure things go as smoothly as possible and provide better accessibility into your hospital and local services.

Please contact the key worker if you wish to discuss any aspects of your treatment.

---

**Holistic assessment**

Each individual has their own experience of cancer and how they feel it affects their lives. Being diagnosed with cancer can make you feel many different emotions and experience unpleasant physical symptoms. You will have received a holistic needs assessment during treatment at the Royal Free Hospital. The holistic needs assessment can be repeated each time you visit a clinic to re-assess these needs or if you have any concerns you would like to discuss.

**Cancer counselling service**

When you or someone close to you has a tumour or cancer you may have concerns, worries, confusion or feelings that distress you. You might many feelings following your cancer treatment, some people are relieved and ready to put the cancer behind them and get back to normal life. But others find it difficult to move on. Adjusting to life after cancer can take time. It is often after treatment that the emotional impact of what you have been through hits them.

You may find it useful to speak to a counselor / psychotherapist or psychologist nearer your local hospital. You can ask your CNS there to refer you to these services. They will know about the services available.

**The Macmillan Cancer information and support centre**

The Macmillan Cancer information and support centre offers up to date, good quality and appropriate information about every aspect of cancer. If you have questions about cancer you can talk to an information specialist face to face in a relaxed informal environment.

Most Macmillan cancer information centres are managed by a Macmillan Cancer information specialist who is supported by trained volunteers. Macmillan can help to offer you advice and support on a wide range of issues.

For further information on your local Macmillan information centre please contact Macmillan on 0808 8080000 or visit macmillan.org.uk

**Try to lead a healthy lifestyle**

After cancer treatment many patients choose to make changes which can help speed up recovery and improve your wellbeing. These include:

- getting some regular exercise.
- Giving up smoking (if you smoke)
- keeping to a health weight
- Cutting down on the amount of alcohol you drink
What else should I look out for in relation to my kidney cancer?

You should contact your GP if you:

• See any blood in your urine
• On-going pain at the wound site not relieved by painkillers

Treatment summary

These summaries the treatment received, from diagnosis through to the end of the treatment. They provide details of diagnosis, treatment and results following surgery and possible symptoms that may occur in the future.

These have been developed to help ensure that GPs are able to best support individuals in the community and to provide important information they may need in other healthcare settings.

A treatment summary will be given to all patient following surgical treatment or sent in the post shortly afterwards.

Your key worker

All patients diagnosed with a cancer will have a key worker who is usually the clinical nurse specialist (CNS). Your key worker will:

• Support you and your family at all stages during your illness
• Provide verbal and written information about your condition and treatment
• Co-ordinate your care
• Provide health education

Your key worker will now be the clinical nurse specialist at your local hospital to ensure things go as smoothly as possible and provide better accessibility into your hospital and local services.

Please contact the key worker if you wish to discuss any aspects of your treatment

<table>
<thead>
<tr>
<th>Clinical nurse specialist at your local hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name: Tel no:</td>
</tr>
</tbody>
</table>

Holistic assessment

Each individual has their own experience of cancer and how they feel it affects their lives. Being diagnosed with cancer can make you feel many different emotions and experience unpleasant physical symptoms. You will have received a holistic needs assessment during treatment at the Royal free hospital. The holistic needs assessment can be repeated each time you visit a clinic to re-assess these needs or if you have any concerns you would like to discuss.

Cancer counselling service

When you or someone close to you has a tumour or cancer you may have concerns, worries, confusion or feelings that distress you. You might many feelings following your cancer treatment, some people are relieved and ready to put the cancer behind then and get back to normal life. But others find it difficult to move on. Adjusting to life after cancer can take time. It is often after treatment that the emotional impact of what you have been through hits them.

You may find it useful to speak to a counselor / psychotherapist or psychologist nearer your local hospital. You can ask your CNS there to refer you to these services. They will know about the services available.

The Macmillan Cancer information and support centre

The Macmillan Cancer information and support centre offers up to date, good quality and appropriate information about every aspect of cancer. If you have questions about cancer you can talk to an information specialist face to face in a relaxed informal environment.

Most Macmillan cancer information centres are managed by a Macmillan Cancer information specialist who is supported by trained volunteers. Macmillan can help to offer you advice and support on a wide range of issues.

For further information on your local Macmillan information centre please contact Macmillan on 0808 8080000 or visit macmillan.org.uk

Try to lead a healthy lifestyle

After cancer treatment many patients choose to make changes which can help speed up recovery and improve your wellbeing. These include:

• getting some regular exercise.
• Giving up smoking (if you smoke)
• keeping to a health weight
• Cutting down on the amount of alcohol you drink
It’s a good idea to look at reducing stress in your life and try to relax more. Macmillan may be able to support you adjusting to life after cancer.

**Help with the cost of cancer**
If you are affected by cancer, the last thing you want to think about is money. Having financial worries while dealing with a cancer diagnosis can be very difficult.

Advice and support is available from:
- Macmillan cancer support 080 8808 0000
- Jobcentre Plus benefits line 080 0055 6688
- Benefits enquiry line 080 088 2200
- www.directgov.gov.uk
- Age UK advice line 080 0169 6565

Your key worker can give you further information and refer you to the service if needed. For further information on your local Macmillan information centre please contact Macmillan on 080 8808 0000 or visit macmillan.org.uk

**Free prescriptions for cancer patients**
All patients diagnosed with a cancer are eligible to free prescription. Application form ‘FP92A’ can be obtained from your clinical nurse specialist or your GP. Complete the exemption form, ensure the doctor or nurse has signed it and send it to the address on the form.

NHS Help with Health Costs, Medical Exemption, Bridge House 152 Pilgrim street, Newcastle Upon Tyne NE1 6SN

Before your exemption certificate arrives, whenever you pay a prescription charge remember to ask your pharmacist for a FP57 NHS receipt and refund claim form

**Complementary therapy**
Complementary therapies are used alongside medical treatments with the aim of providing psychological and emotional support through the relief of symptoms. Massage therapy can benefit patients by, promoting relaxation, reducing anxiety, ease symptoms such as pain nausea and poor sleep patterns.

---

**Kidney cancer Support group**
A support group can be of great benefit to patients, family and carers helping to increase knowledge of kidney cancer and allowing patients to share their experiences with each other. The Royal Free centre organises a patient and family support group every six- eight weeks. Invited expert guest speaker present on a specialist subject followed by tea and coffee. An invitation is sent to all new patients diagnosed at the Royal Free London

**London Cancer directory of services** is now live on our website and can be accessed here: http://londoncancer.org/cancerprofessionals/directory-of-services/

**Patient advice & liaison service (PALS)**
The PALS team is part of the nursing directorate. The opening hours of the office are 10am-4pm Monday-Friday.

PALS is a ‘one stop shop’ offering advice, information and help to patients and their families who experience problems using or accessing the trust’s services. PALS aims to resolve complaints and concerns quickly.

020 7794 0500 RFH ext 33281/34339
It's a good idea to look at reducing stress in your life and try to relax more. Macmillan may be able to support you adjusting to life after cancer.

Help with the cost of cancer
If you are affected by cancer, the last thing you want to think about is money. Having financial worries while dealing with a cancer diagnosis can be very difficult.

Advice and support is available form:

Macmillan cancer support 080 8808 0000
Jobcentre Plus benefits line 080 0055 6688
Benefits enquiry line 080 088 2200

www.directgov.gov.uk
Age UK advice line 080 0169 6565

Your key worker can give you further information and refer you to the service if needed. For further information on your local Macmillan information centre please contact Macmillan on 080 8808 0000 or visit macmillan.org.uk

Free prescriptions for cancer patients
All patients diagnosed with a cancer are eligible to free prescription. Application form ‘FP92A’ can be obtained from your clinical nurse specialist or your GP. Complete the exemption form, ensure the doctor or nurse has signed it and send it to the address on the form.

NHS Help with Health Costs, Medical Exemption, Bridge House 152 Pilgrim street, Newcastle Upon Tyne NE1 6SN

Before your exemption certificate arrives, whenever you pay a prescription charge remember to ask your pharmacist for a FP57 NHS receipt and refund claim form

Complementary therapy
Complementary therapies are used alongside medical treatments with the aim of providing psychological and emotional support through the relief of symptoms. Massage therapy can benefit patients by, promoting relaxation, reducing anxiety, ease symptoms such as pain nausea and poor sleep patterns.

Kidney cancer Support group
A support group can be of great benefit to patients, family and carers helping to increase knowledge of kidney cancer and allowing patients to share their experiences with each other. The Royal Free centre organises a patient and family support group every six- eight weeks. Invited expert guest speaker present on a specialist subject followed by tea and coffee. An invitation is sent to all new patients diagnosed at the Royal Free London

London Cancer directory of services is now live on our website and can be accessed here: http://londoncancer.org/cancerprofessionals/directory-of-services/

Patient advice & liaison service (PALS)
The PALS team is part of the nursing directorate. The opening hours of the office are 10am-4pm Monday-Friday.

PALS is a ‘one stop shop’ offering advice, information and help to patients and their families who experience problems using or accessing the trust’s services. PALS aims to resolve complaints and concerns quickly.

020 7794 0500  RFH ext 33281/34339
Useful sources of information and support

Additional information available

Kidney Cancer UK
Provides information and support for kidney cancer patients and their carers
www.kcuk.org 0844 870 7054

James Whale Fund for Kidney Cancer
Helps to increase knowledge and awareness of kidney cancer
www.jameswhalefund.org 0844 474 5050

Kidney Cancer Support Network
Helps patients’ family and friends to join together for information and advice
www.kidneycancersupportnetwork.co.uk 0120 989 0326

Cancer Research UK
www.cancerhelp.org.uk  080 800 4040

Macmillan Cancer Support
Information on living with the practical, emotional and financial effects of cancer
www.macmillan.org.uk 080 880 8000

Marie Curie Cancer Care
www.mariecurie.org.uk 020 7235 3325

London Cancer
www.londoncancer.org

Your key worker at the Royal Free London can be contacted on

Clinical nurse specialist contact details: 0207 317 7779
Email: rfh.renalcancersnursing@nhs.net