

**Appendix C: Event material
(Phase two engagement)**



Improving specialist
cancer
and

in north and east London and west Essex



cardiovascular
services

Commissioners' preferred options

Improving Specialist Cancer and
Cardiovascular Services in North
and East London and West Essex

Travel & Transport Analysis

















The above images were displayed at engagement workshops

UCLH patient **Tom Clarke** was one of the first to benefit from the first four star hotel in the NHS which helps make cancer treatment easier for people travelling long distances.



Tom, 28, is from Maidstone in Kent – around 90 minutes away from University College Hospital.

He said:

“It was well worth making the journey into London because it meant I am getting the specialist care I need for my particular cancer.

“Being able to stay in the Cotton Rooms really helped and meant I could be more independent throughout my treatment. It’s good for the hospital because it’s cheaper than a hospital bed and it’s good for the patient because staying in hospital can be depressing.

“I like the layout, the colours and there’s a chilled out, cosy atmosphere. Best of all though is the freedom – I can come and go as I please. I live in Maidstone so it’s a bit far to travel each day when I’m having treatment and the hotel is far better than staying in a hospital ward.”

Kirit Ardeshta , Consultant Haematologist and Clinical Lead for the Cancer Centre, said:

“It is a successful and alternative way of delivering treatments to cancer patients who would historically have been kept in hospital unnecessarily.

“Patients are overwhelmingly positive about the service as it gives them the freedom to carry on with a ‘normal’ life in an environment where family and children can stay with them.

“All patients must meet strict criteria and if our medical teams consider that a patient needs to be admitted to hospital then a hospital bed is always provided.”

The Cotton Rooms – a boutique hotel and the first of its kind in the NHS - offers a warm, personalised service normally found in good quality hotels but also provides touches of luxury to help patients retain their independence while undergoing clinical tests and treatments.

This is known as ‘ambulatory care’ and patients who receive this treatment are monitored every day. The ambulatory care team may be contacted 24 hours a day and to make this easier, all guest rooms have telephones with direct lines to the hospital switchboard. For emergency situations there is also an additional alarm by the bedside.



Patient transport services

Barts Health, in partnership with ERS Medical, the UK's largest provider of independent ambulance services provides a transport service for eligible patients. The service is primarily for non-emergency and high dependency users.

ERS Medical focuses on patient experience as a critical measure of service quality, recognising that those individuals using the patient transport service are often vulnerable patients or have long term conditions. Together, our goal is to make patient transport the element of a patient's pathway that they remember the least.

This service went operational on 1 June 2014 across Barts Health, replacing the previous 14 providers, and offering a single point of booking for all needs in the organisation. Our commitment is to further enhance the service that we provide.

Barts Health also works extremely closely with the London Ambulance Service.

Where to get more information

If you need further information on travelling to St Bartholomew's please speak to a member of staff.

You could also be eligible for assistance if you receive benefits or tax credits. For example: income support; job seekers allowance. Your local council will also be able to provide information on eligibility and how to apply for a disabled parking badge.

Large print and other languages

For this leaflet in large print, please ring 020 3594 2040 or 020 3594 2050.

For help interpreting this leaflet in other languages, please ring 020 7377 7280.

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Switchboard: 020 3418 5000
www.bartshealth.nhs.uk



Patient information

Barts Heart Centre,
St Bartholomew's Hospital

Transport Information



Following a longer inpatient stay, transport will be arranged, if required, by the ward staff who will assess your transport needs on discharge.

Cancellation

If your appointment is cancelled by the hospital or you can not attend it, please ring us on 020 3456 7010 to cancel your transport.

Can an escort be arranged to accompany me in hospital transport?

This will depend on your clinical condition or mobility. If you meet the criteria then an escort will be booked to accompany you to and from the hospital. However, we aim to keep these to a minimum as escorts take up seats that would otherwise be used for patients.

Types of vehicle

- An ambulance car or ambulance bus for patients with restricted mobility
- An ambulance bus or a stretcher ambulance

Our Quality Standards

We aim to ensure that 95% of patients who use hospital transport arrive at the hospital no earlier than 45 minutes before and no later than 15 minutes after their appointment time. We also aim to ensure that 95% of patients leave hospital within 60 minutes of reporting ready to the transport desk.

Putting patients first

All our transport staff are committed to treating patients with dignity and respect. They will always be welcoming, ensure your journey as easy as possible, and give you any assistance that you need.

If you wish to comment on our patient transport services, please complete a "Patient and Visitor" comment card and place it in one of our grey comment boxes, or write to:

Mr Ridha Gabsi, Transport Services Manager:
Address: Transport Department,
250 Euston Road,
London NW1 2PG

Email: ridha.gabsi@uclh.nhs.uk

Contact details

Transport assessment-booking team:
Telephone: 020 3456 7010
Monday to Friday
09:00 to 17:00

Address: Complaints Department,
2nd Floor West,
250 Euston Road,
London NW1 2PG

If you would like a large print, audio or translated version of this document please ring 020 3456 7010. We will try our best to meet your needs.



We are committed to
delivering top-quality patient
care, excellent education
and world class research

Safety
Kindness
Teamwork
Improving



University College London Hospitals

The patient transport service Transport Department



University College Hospital

Reclaiming the congestion charge Information for patients attending NHS appointments at UCLH

How do I pay the Congestion Charge? For details of how to pay, contact Congestion Charging at Transport for London (TfL) on 0845 900 1234 or at www.cclondon.com
Information for Blue Badge holders If you hold a valid Blue Badge parking permit you are eligible for a 100 per cent discount from the charge, once you have registered with Congestion Charging. How do I register with Congestion Charging? To register for the discount you must complete an application form, provide supporting documents and pay a fee (£10 at time of print). You cannot claim back this registration fee. The £10 fee also applies if your previous discount expired more than 90 days ago. TfL remind you to continue paying the full daily charge until you receive your registration approval letter. Full details of the application process, including the form, are available at www.cclondon.com or by calling 0845 900 1234.

Information for patients without a Blue Badge If I have an NHS appointment at UCLH can I reclaim the Congestion Charge? If you match the criteria you can reclaim the daily charge from UCLH. You will need to pay the charge first and then claim it back at the hospital. What are the reimbursement criteria? You must: • have a compromised immune system or • require regular therapy or assessment or • require recurrent surgical intervention and • be clinically assessed as too ill, weak or disabled to travel to an appointment on public transport. Who assesses if I match the criteria? Your clinician e.g. your hospital doctor uses this criteria to check if you are able to reclaim the charge. How do I reclaim the charge? 1. Pay the charge. TfL recommend paying on the day you travel, not in advance, in case your appointment is cancelled. 2. Keep your Congestion Charging receipt or make a note of the receipt number.

3. Ask for a Congestion Charging patient claim form when you arrive in the department for your appointment if one vehicle you travel to your appointment in is registered for Congestion Charging Auto Pay, etc. 4. Ask the doctor or healthcare professional who is seeing you to complete the form. 5. Take the form, your Congestion Charging receipt (or receipt number) and vehicle registration number to the Cashiers Office (details below).

Please note In Section B of the claim form ('Category of Claim') both box one and box two must be signed by your clinician for you to receive your payment. If you do not pay the Congestion Charge you will be charged. You will not be reimbursed for your Penalty Charge (PCN). Where do I go to collect my payment? Take your form and details along with you to your appointment. Payments can be collected from the Cashiers Office at the hospital you're attending: University College Hospital: (Ground floor) Opening times: Monday to Friday 09:00 to 17:00 Telephone: 020 3447 9898 The National Hospital for Neurology and Neurosurgery: (Ground floor) Opening times: Monday to Friday 09:00 to 13:15 and 14:00 to 17:00 Telephone: 020 3448 8870 The Royal London Hospital for Integrated Medicine: (Ground floor) Opening times: Monday to Friday 09:00 to 13:15 and 14:00 to 17:00 Telephone: 020 3448 8941



THE SPECIALIST CENTRE FOR KIDNEY CANCER AT THE ROYAL FREE

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INTRODUCTION

The specialist centre for kidney cancer at the Royal Free is an expert centre which leads and coordinates the care of people with kidney cancer. Patients with a non-cancerous tumour will also be seen in the centre.

We recognise that the time after a cancer or tumour diagnosis will be a worrying one for you and your family. We hope this brochure will help you understand the treatment plan that you will follow after your diagnosis, as well as introduce the type of healthcare professionals you will meet along the way.



The specialist centre has been created to lead and coordinate the care of people with kidney cancer across north central London and west Essex.

People with kidney cancer will benefit from:

- the dedicated and highly specialised services available at the Royal Free
- a coordinated pathway from diagnosis through to treatment and aftercare
- support from one and sometimes two, dedicated clinical nurse specialists who will be with you throughout the patient journey.

We have a website that contains more detailed information about the centre and treatments that are available:
www.royalfree.nhs.uk/urology/kidneycancerservice

Support is also available from a patient navigator who will advise you about:

- transport
- parking
- accommodation arrangements
- hospital appointments
- and any other administration issues

to make sure your journey to the Royal Free and your time here is as smooth and comfortable as possible.

Contact details for the patient navigator are:

Direct telephone:
020 7317 7779

Email:
rfh.kidneycancer@nhs.net

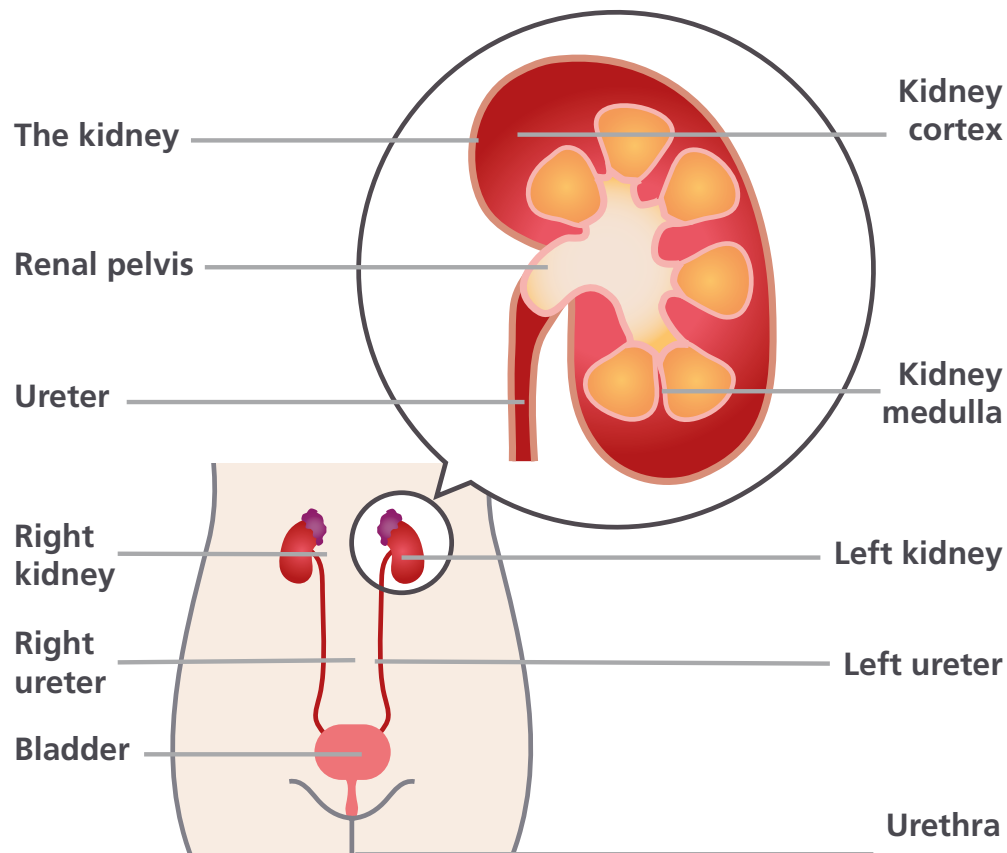
(Ensure this is placed below the last paragraph and not under the photo as currently displayed)

THE KIDNEYS

The kidneys are two bean shaped organs about the same size as a fist. They are near the middle of the back, one on either side of the spine.

The kidneys are part of the body system called the urinary system. This system filters waste products out of the blood and makes urine.

Urine drains from each kidney, through a tube called a ureter, to the bladder where it is stored. When you're ready to pass urine it leaves the body through another tube called the urethra.



Blood is carried to the kidney through a blood vessel called the renal artery. Renal means 'to do with the kidney'. After the blood has been filtered by thousands of tiny filters called nephrons, it travels back to the rest of the body through the renal vein.

It is important to note that all normal renal functions can be maintained by one kidney. For example, a person who is born with only one kidney or who donates a kidney for organ transplantation can still live a perfectly healthy life. Similarly, a kidney cancer patient who has one kidney removed by surgery will not necessarily suffer any significant impairment of overall renal function.

SPECIALIST MULTIDISCIPLINARY TEAM CLINIC (SMDT CLINIC)

You have been referred to the specialist centre for kidney cancer at the Royal Free to discuss your treatment. Depending on your treatment options you may meet some or all of the team at your appointment (a surgeon, a radiologist, a clinical nurse specialist (CNS) and/or an oncologist). The clinical nurse specialist will be your main point of contact throughout your treatment at the Royal Free. The patient navigator will assist you with queries about getting to the appointment, and help with changing clinic appointments if required (tel: 020 7317 7779).

You may have further tests at this appointment and will be able to get information about your options for treatment from each of the appropriate specialists.

Wherever possible we will aim to do your pre-assessment tests for surgery at this appointment and agree a date for your treatment.

At the end of this brochure you will find an example of questions that you may find useful to ask at your appointment. You are recommended to write down and bring with you any of your concerns to discuss with the team at the appointment or you can contact the clinical nurse specialist after the appointment – contact details are given later in this brochure.

PLEASE NOTE YOU SHOULD ALLOW 2 – 3 HOURS FOR YOUR FIRST APPOINTMENT. We would encourage you to bring a partner, friend or relative to this appointment

Specialist multidisciplinary team meeting

This is a weekly video conference meeting which links your local hospital and other hospital sites/specialists for discussion about your treatment. The meeting enables all team members to discuss every new patient with a renal cancer and where appropriate, agree staging (an indication of where the cancer is located) and plan further investigations and/or treatments. Existing patients requiring a change of treatment are also discussed at these meetings.

An SMDT recommendation is made for each new patient (or patients requiring a change of treatment), and the options for treatment will be discussed with you at the clinic.

The SMDT may recommend that further tests are necessary, in which case you will be contacted to explain the need for this.

Specialist multidisciplinary team (SMDT)

At the Royal Free you will be looked after by a specialist multidisciplinary team (SMDT). The SMDT consists of doctors, nurses, and coordinators who all have specialist training and experience in diagnosing, treating and supporting patients with kidney cancers.

The team includes:

Urologist (a surgeon who specialises in kidney cancer)

Interventional radiologist (specialist doctor in non surgical treatment)

Clinical oncologist (specialist doctor in cancer treatments such as chemo)

Radiologist (a specialist doctor who works with x-rays and diagnostic scans)

Histocytopathologist (who looks at tissue samples and cells to diagnose cancer)

Clinical nurse specialist, your key worker (a registered nurse with specialist qualifications and skills)

Research nurses / research practitioners
Specialist nurse who looks after patients in clinical trials



MDT coordinator (responsible for ensuring patient names and details are provided for the team at the SMDT meeting by liaising with clinical and administrative teams across departments and referring hospitals)

Patient navigator (administrative staff who work to ensure appointments are scheduled appropriately and support patients in booking and providing information about appointments)

TREATMENT OPTIONS

More detailed written information will be given to you when you attend the clinic but the types of treatment options are described here:

Surgery

Is the most common treatment for a kidney cancer or tumour. It can be a cure for an early cancer and part of a treatment for an advanced cancer. Removal of the entire kidney is called a nephrectomy. If the tumour is small the surgeon will remove only part of the kidney, a partial nephrectomy. It is possible to have keyhole surgery which is called a laparoscopic nephrectomy.

Robotic assisted surgery

This is laparoscopic surgery using robotic assistance through the small keyhole incisions. The keyhole instruments and a camera allowing the surgeon to see inside of your abdomen are attached to the robotic arms. The da Vinci robot was introduced to the Royal Free in 2014.

The da Vinci® system is used extensively throughout the US and Europe, and it is currently being used in many different areas of surgery. To date there have been 1.2 million operations performed with the robot.

Cryoablation

Is a technique that destroys tissue, in this case through freezing. In order to produce the freeze, needles are placed into the kidney, using image guidance (for example ultrasound and CT scanning). A mixture of gases is then used to freeze and thaw the tips of the needles.

Both surgery and cryotherapy are performed under general anaesthetic. You will usually receive a pre-assessment test for these procedures during your first clinic appointment or occasionally be given an appointment to attend for this assessment at a later date.

Radiofrequency ablation (RFA)

Uses heat from an electric probe to destroy the tumour. The procedure is usually performed by passing a needle through the skin using image guidance (for example ultrasound and CT scanning).

Following any of the above treatments you will be invited back to the SMDT clinic at the Royal Free to have a check-up appointment

If the consultant is happy with your recovery he will make arrangements for you to have the next appointment at your local hospital. All your future appointments will be at the local hospital. Your point of contact will then be the clinical nurse specialist at your local hospital



Clinical trials

Clinical trials play a very important role in helping search for new and more effective treatments as well as better ways of diagnosing, screening or preventing a disease. Clinical trials are the best way to find out whether or not a new treatment is better than the current standard treatment.

A clinical trial is a medical research study involving people. People taking part in trials are always volunteers. Trials are done in all areas of medicine, not just cancer. They can involve testing new drugs and combinations of drugs, as well as new technology and procedures.

It is possible that there will be clinical trials that are suitable for you. Your medical team should discuss this with you.

BIO banking

Blood or tumour samples may be obtained to assist research. You may be asked to give your permission to use some of your samples for research into cancer.

Immunotherapy

Stimulates the body's own immune system to attack the cancer cells

Targeted therapies

This treatment uses drugs which target blood vessels and growth factors in the cancer cells.

These are used to treat kidney cancer that has spread beyond the kidney. They have side effects and your doctor can give you more detail.

Supportive and palliative care

Is about providing support at all stages of a person's experience with cancer. Supportive care means helping patients and their families cope with cancer and its treatment

YOUR KEY WORKER

All patients attending the SMDT clinic will be appointed 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 work closely with the clinical nurse specialist at your local hospital to ensure things go as smoothly as possible and provide better accessibility into the hospital as he or she can be contacted easily for help and advice.

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

Clinical nurse specialist contact details:

Clinical nurse specialist renal surgery:

07935 450 617
07775 687823

Email:

rfh.renalcancernursing@nhs.net

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. Holistic needs assessment (HNA) is a tool to identify areas of concern and to develop a personalised care plan, with onward referrals made as required. Effective HNA and care planning can help us to meet your individual physical, emotional, practical, family and spiritual needs in a timely and appropriate way. The HNA will be carried out by the clinic nurse specialist at the most appropriate stage of your treatment.

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. There is a counselling service at the Royal Free which you can ask to be referred to.

You might prefer to see a counsellor / psychotherapist or psychologist nearer your local hospital. You can ask your CNS 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.

The centre is managed by a Macmillan Cancer information specialist who is supported by trained volunteers.

The centre is available for anyone affected by or who would like information on cancer, including relatives and friends. If you are worried you may have cancer or are adjusting to life after cancer treatment, they can help you find the information and support you need.

You do not have to be a patient of the Royal Free to access this service.

The centre is located on the ground floor in the oncology out-patients department.

If you are unable to get to the centre you can contact them by phone on 020 7794 0500 ext 31337 or by email cancerinfo@royalfree.nhs.uk

MACMILLAN BENEFITS ADVISOR

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. The Macmillan benefits advisor is available to offer support and guidance.

Your key worker can give you further information and refer you to the service if needed.

COMPLEMENTARY THERAPY

All patients can access the massage and reflexology service at any time during treatment. The nurse or doctor can refer you to this service.

THE INTERPRETING SERVICE

The interpreting service exists for patients who speak little or no English and patients who are deaf or 'hard-of-hearing' and require communication support. A face-to-face interpreter is required for all new appointments and 24 hours' notice is required.

Please contact the patient navigator on 020 7317 7779 who will organise this for you.



HOW TO GET HERE

We recommend that you come by public transport if possible, as parking at the hospital and in the local area is very limited. You can download local walking maps as well as transport maps from the website.

Bicycle parking is available outside the accident and emergency entrance on the lower ground floor. Pay and Display parking areas are available locally but these are very limited and frequently full.

The Kidney and Urology Centre clinic can be found on the 3rd floor (see back of brochure for map)

Rail

Hampstead Heath station is near to the hospital and train services are operated by London Overground. The station is accessible to Oyster pay as you go users.

Underground

Belsize Park tube station on the Northern Line. The Royal Free is slightly uphill for around 150 metres from the station.

Bus

Routes: 24, 46, 168, 268 and C11

Travel information

For detailed travel information and route planning, see the Transport for London journey planner or call Transport for London on 020 7222 1234.

Car parking at the Royal Free

Our parking facilities are operated by a number plate recognition ticketless system. You can pay for parking by cash, card, and phone or by downloading an app.

Payment points are located at both the Pond Street entrance and within Lawn Road car park.

Tel: 0330 400 7275 and follow the instructions quoting site number 79499. The app can be downloaded on www.paybyphone.co.uk using site number 79499.

Charges are £3 per hour (no part hours) – applicable 24 hours a day, 7 days a week.

A limited number of parking spaces are available for kidney cancer patients and these are allocated according to need. The patient navigator can provide further advice on booking one of these spaces. (Tel: 020 7317 7779)

Can you be dropped off?

Yes cars can drop and collect you from the hospital entrance in Pond Street but they cannot double park or wait there for more than 20 minutes.

Hospital transport

Some people are entitled to hospital transport. If you need hospital transport on medical grounds this is usually organised by your GP for your first visit. You are collected up to two hours before your appointment time, so please be ready in plenty of time.

When you arrive at your clinic, tell the receptionist that you came by hospital transport so that we can arrange your return journey. If you have any problems, call the hospital's transport office on 020 7472 6572.

Can you claim expenses?

If you receive income support, income-based jobseeker's allowance, pension credit, working tax credit or child tax credit, you can claim back your public transport fares to and from the hospital. This does not cover taxi services. Ask the clinic to give you a fares claim form (which they should fill in for you). Take the form to the hospital's cashier office in the finance department on the lower ground floor. Please bring your benefit book or other current evidence that you are receiving the benefit and your travel tickets.

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

QUESTIONS YOU MAY WISH TO ASK YOUR SPECIALIST TEAM

- ▶ What is a kidney tumour?
- ▶ What is the difference between a benign tumour and a cancerous tumour?
- ▶ What kind of kidney cancer do I have?
- ▶ Do you think my cancer has spread?
- ▶ What is the stage of my cancer and what does that mean?
- ▶ What treatment choices do I have?
- ▶ What do you recommend and why?
- ▶ What risks or side effects are there to the treatments you suggest?
- ▶ What type of follow-up will I need after treatment?
- ▶ Are there any clinical trials I should think about?

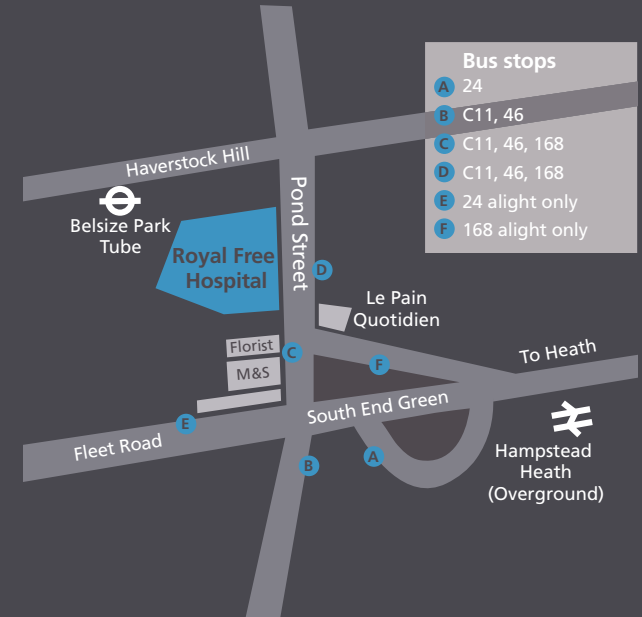
You might also want to think about your quality of life while you are having treatment. Will you have to travel back and forth to hospital? What are the side effects of treatment? Can the side effects be treated?

Along with these sample questions, be sure to write down some of your own.

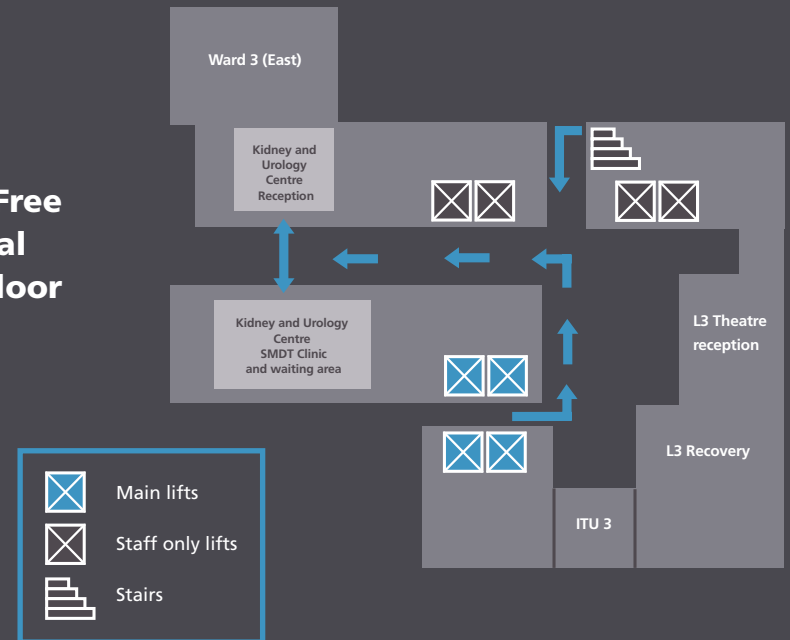
For example, you might want to know how long it might take you to recover so that you can plan your work schedule.

Or you might want to ask about second opinions or about clinical trials for which you may qualify.

How to get to the Royal Free Hospital



Royal Free Hospital third floor



**Hospitals that are part of the
specialist centre for renal cancer at
the Royal Free**



Barnet and Chase Farm Hospitals NHS Trust

North Middlesex Hospital

The Princess Alexandra NHS Trust

Whittington NHS Trust

University College London Hospitals

If you would like a large print or audio version of this information,
please ask a member of staff.