



Royal Papworth Hospital
NHS Foundation Trust

Moving to an adult transplant unit

Great Ormond Street Hospital (GOSH)
- Royal Papworth Hospital

A patient's guide

Moving into adult care from paediatric care can also be known as a 'transition'.

'Transition' is a term used by the medical profession to describe the way in which your care changes in the hospital setting.

It is a time when you need to understand how your condition affects you, start to take control of the medication you take and make decisions for yourself regarding your health.

Remember that this process is not going to be easy for your parents or those who have looked after you up to now. Whilst still being supportive, your parents will need to accept less responsibility during the decision-making process.

This leaflet will try to give you the information you require before making a decision to move to the adult transplant service at Royal Papworth.

Prior to your transition, you will be given the opportunity to be seen jointly with both the GOSH and Royal Papworth teams. Both teams will discuss with you and your parents the changeover and answer any questions you have.

You will also have the opportunity to visit Royal Papworth and the Transplant Continuing Care Unit (TCCU) informally before you move from GOSH. You can arrange this by contacting TCCU on 01223 638007.

Transition to Royal Papworth

When you have decided you would like to be transferred to Royal Papworth Hospital, they will receive a full record from GOSH of your previous operations and visits, which will become part of your new notes.

When Royal Papworth receives a formal referral letter about you, the consultant in charge will look at all information included within the referral documents. If any further information is needed, GOSH will be asked to send it through prior to your visit.

The TCCU team then arranges for Royal Papworth medical and nurses notes to be made up.

Your initial appointment will be sent out by TCCU including details of how to find the Transplant Unit. If the appointment is unsuitable, please feel free to

contact us and we will find a more suitable date for both the patient and the Transplant Unit.

Your outpatient visits

You will not find your outpatient visits to Royal Papworth very different to GOSH, and even though you are now attending an adult centre, your parents (if you wish) can come with you to see your consultant as they did at GOSH. However, many patients choose not to. As an adult, doctors are not legally allowed to discuss your care with anybody, not even your parents, without your permission.

Outpatient clinics are carried out in TCCU and are held on Monday, Tuesday, Wednesday and Thursday mornings. On the morning of your clinic visit you should arrive by 08:00. On arrival, you will be greeted by one of the outpatient administrators.

The following tests are carried out during your clinic visit:

Nursing assessment

You will have your blood pressure and weight taken by the named nurse within the clinic you are attending. The clinic nurse will also talk through your medication with you and any other issues you may wish to discuss such as health promotion and lifestyle.

Blood test

It is important that you do not take your Tacrolimus, Neoral or Sirolimus until after your blood test.

ECG

Chest X-ray

Echo

These are usually carried out yearly if you have had a heart transplant)

Lung Function (if you have had lung transplantation)

Following all of your tests, you will be seen by the consultant and the transplant nurse, and you will be given the opportunity to ask questions.

The frequency of your appointment is usually four to six months if you are well after two to three years post transplant. However, this is assessed on an individual basis and some people may need to be seen more frequently. If you do not attend your appointment you will be contacted by one of the transplant nurses or clinic co-ordinators.

Following your clinic visits, your GP will receive a copy of your clinic letter. A copy may also be sent to you if you wish. Please ask one of the clinic co-ordinators if you would like to receive them.

Blood test results

The transplant nurse will call you with any changes to your medication - this usually occurs the following day. It is important to note that we do not phone you if there are no changes to be made.

Occasionally, we may ask you to get your bloods checked inbetween clinic visits. If this is the case, we will ring phone and then send out the appropriate letter and form for you to take to your GP or practice nurse.

Heart transplant recipients

Coronary angiograms on heart transplant patients are only carried out at two and five years. Thereafter, it is repeated at five yearly intervals unless you present with any symptoms. This is generally carried out as a day case admission and you will be at the hospital for about six to eight hours. The other difference is that at the adult centre, angiograms are performed under local anaesthetic and not general anaesthetic. In some patients, we are performing CT scans instead of angiograms. If you require endomyocardial biopsies (which are only performed if clinically necessary due to concerns over rejection) they are again generally carried out under local anaesthetic.

Lung transplant recipients

You will be seen at regular intervals, and annual reviews do not involve a bronchoscopy or biopsy unless indicated. However, it is important that lung transplant recipients have a bone scan every two years and CT scans may be requested as part of this review process. Bronchoscopies and transbronchial biopsies are

carried out with intravenous sedation and you will be requested to stay overnight.

Inpatient admissions

If you require an inpatient admission you will be admitted onto either floor 4 or 5. During your inpatient stay you will be expected to self-medicate.

Both ward areas are mixed sex and age. They consist of single en-suite rooms.

Accommodation is not available for parents, partners or friends. However, there are a number of B&Bs/hotels in Cambridge. Please ask for a list should you require accommodation.

Telephone help line

The TCCU runs a telephone help line staffed by the transplant nurses, open from 08:00-17:00, Monday-Friday. Out of those hours there is always a transplant doctor on-call to answer any questions or concerns you may have. The on-call transplant doctor has 24 hour access to your medical notes and also to the consultant in charge of your care.

You can contact this doctor via the main hospital switchboard on 01223 638000.

This help line is accessible to all. Parents can call and speak with one of the transplant nurses or the on-call doctor (out of hours).

It should be noted that as you are now at an adult centre, no confidential information would be divulged unless you have requested us to do so. Wherever possible we encourage you to make contact yourself, with your parents' knowledge and support.

Moving away from home

If you are moving away from home to university or college, it is important to register with the resident GP. If you have problems getting your medication from your resident GP you can telephone TCCU and we can send you a prescription in the post. Please make sure you have two weeks' supply of your medication at all times.

Social calendar

Transplant Times

Here at Royal Papworth we have a patient newsletter which is sent out twice yearly. All patients receive a copy of this and you are welcome to contribute to its content. Please contact the database manager through the hospital switchboard on extension 638330.

Transplant games/sport

Would you like to join the Royal Papworth Transplant team? You really don't have to be sporty to take part. It is good fun and helps to promote awareness of the desperate need for more donors.

If you are interested and would like more information, please contact our team manager, Margaret Gambrill, at royalpapworthtransplantsport@gmail.com.

Further information

Main hospital switchboard: 01223 638000.

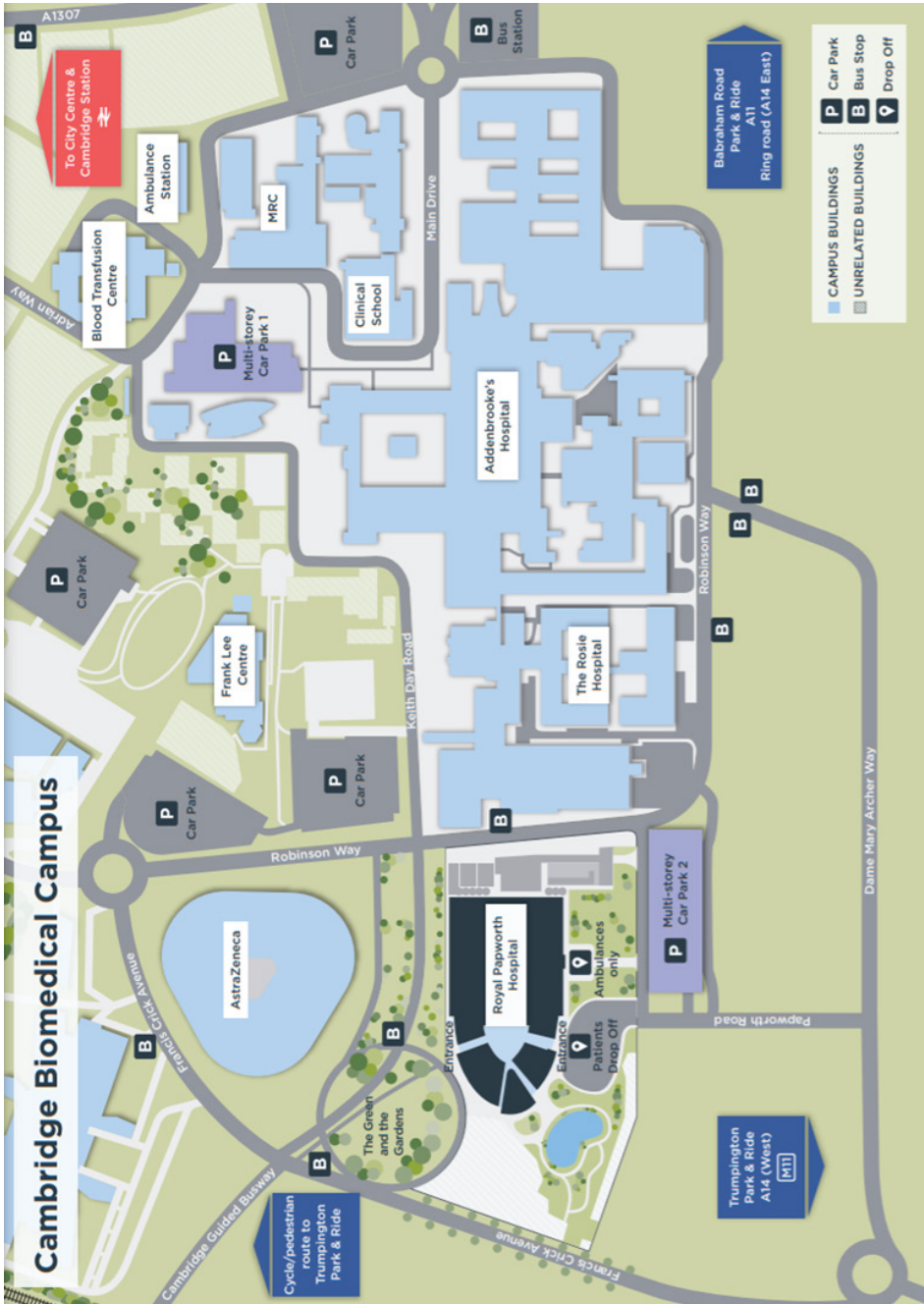
Transplant Continuing Care Unit: 01223 638007.

TCCU email: papworth.transplant.continuingcare@nhs.net

Further information regarding the transplant unit can be found on the Royal Papworth Hospital NHS Trust web site at <https://royalpapworth.nhs.uk/>

The preferred method of contact is by telephone. All calls will be returned on the same day if possible.

Cambridge Biomedical Campus



Royal Papworth Hospital NHS Foundation Trust
Papworth Road
Cambridge Biomedical Campus
Cambridge
CB2 0AY

Tel: 01223 638000

www.royalpapworth.nhs.uk

A member of Cambridge University Health Partners

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Department: TCCU
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