

Moving to an adult transplant unit

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/guardians or those who have looked after you up to now. Whilst still being supportive, your parents/guardians will need to accept less responsibility during the decision-making process.

This leaflet will provide you with information to aid your decision making about transitioning to the adult transplant service at Royal Papworth Hospital.

Prior to your transition, you will be given the opportunity to be seen jointly with both the Great Ormond Street (GOSH) and Royal Papworth Hospital teams. Both teams will discuss with you and your parents/guardians the changeover and answer any questions you have.

You will also have the opportunity to visit Royal Papworth informally before you move from GOSH. You can arrange this by contacting TCCU on 01223 638007 (see further contact details below).

Transition to Royal Papworth

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

When we receive 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 initial visit.

The transplant team will arrange for Royal Papworth medical and nurses notes to be made up.

Your initial appointment will be sent out by the outpatients bookings team including details of how to find the hospital and the outpatients department. If the appointment is unsuitable, please contact the bookings team.

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 or guardians (if you wish) can come with you to see your consultant as they did at GOSH.

However, many patients choose not to do so. As an adult, doctors are not legally allowed to discuss your care

with anybody, not even your parents or guardians, without your permission.

Outpatient clinics 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 an outpatient administrator.

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. The following tests will be carried out:

- **Blood test**
It is important that you do not take your tacrolimus, Neoral or sirolimus until after your blood test.
- **Electrocardiogram (ECG)**
- **Chest X-ray**

- **Echocardiogram**
(If you have had heart transplant. These are usually carried out yearly)
- **Lung function**
(if you have had a lung transplant)

Following these 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 appointments are 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 will also be sent to you and another copy also forwarded to GOSH.

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 in-between clinic visits. If this is the case, we will ring you and then send out the appropriate letter for you to take to your GP or practice nurse.

Heart transplant recipients

Coronary angiograms on heart transplant patient are only carried out at two and five years. This is a procedure to look at the blood vessels of the heart by placing a fine tube into an artery that supplies the heart muscle, and injecting a special dye whilst taking X-ray pictures.

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.

At the pediatric centre this procedure would have been carried out under general anaesthetic. However, at the adult centre, angiograms are performed under local anaesthetic. This is where you will be awake but the area where the catheter is inserted will be numb.

For some patients, we perform CT scans instead of angiograms. If you require endomyocardial biopsies (a procedure to remove a small amount of heart tissue, which would only be performed if clinically necessary due to concerns over rejection) these are again generally carried out under local anaesthetic.

Lung transplant recipients

You will be seen at regular intervals as an outpatient. These appointments do not routinely involve an admission for a bronchoscopy or biopsy unless clinically indicated. It is important that lung transplant recipients have a

bone scan every two years. This is to ensure that your bone density has not been affected by your transplant medication. CT scans may be requested as part of this review process.

A bronchoscopy is a procedure to assess the airways and lungs through a thin, lighted tube with a camera, inserted via the mouth or nose. Transbronchial biopsies are where a small amount of lung tissue is removed for testing. Bronchoscopies and transbronchial biopsies are carried out with intravenous sedation and you will need to stay overnight. The sedation medication that you will be given will make you feel relaxed but will not put you to sleep.

Inpatient admissions

If you require an inpatient admission, you will be expected to self-medicate during your stay.

Ward areas are mixed sex and age, however they consist of single en-suite rooms.

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

Telephone help line

The transplant continuing care unit (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 co-ordinator to answer any **urgent** questions or concerns.

You can contact the transplant coordinator via switchboard 01223 638000.

This helpline is accessible to all. Parents/guardians can call and speak with one of the transplant nurses or the transplant coordinator (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'/guardian's knowledge and support.

Medication

During your first appointment the team will ask you to sign a form consenting to home delivery of your immunosuppression medication. This can take a couple of weeks to set up, so you should ensure that you have enough medication before leaving the appointment. Immunosuppression will be supplied by Royal Papworth; all of your other medication will be supplied by your GP.

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 during working hours.

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 visit:

transplantsport.org.uk

britishtransplantgames.co.uk or you can join our heart and lung transplant sport team on Facebook.

Further information

Main hospital switchboard: 01223 638000.

TCCU: 01223 638007 open from 08:00-17:00, Monday-Friday.

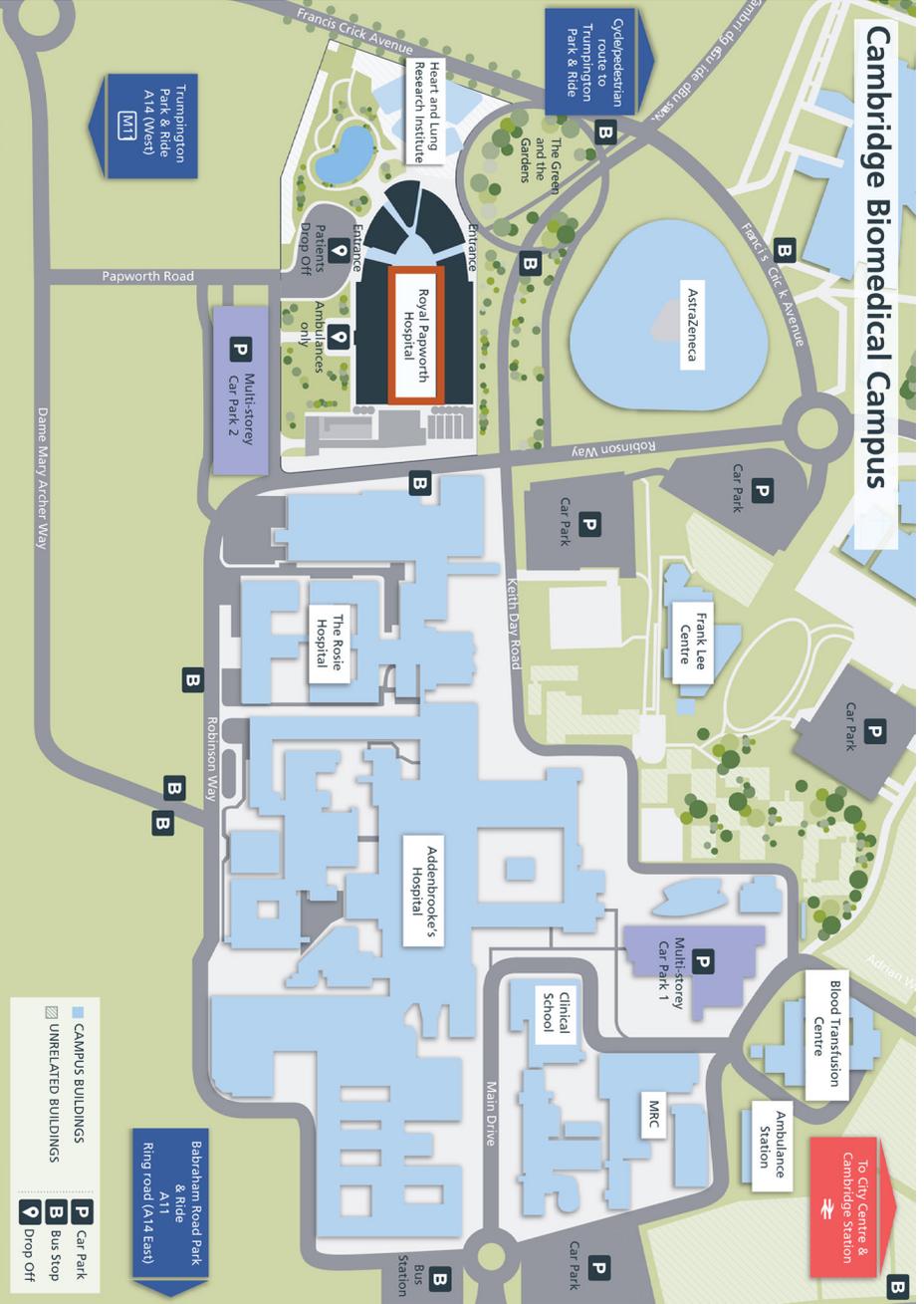
TCCU email: papworth.transplant.continuingcare@nhs.net

Further information regarding the transplant unit can be found on:

royalpapworth.nhs.uk/our-services/surgery/transplant-services

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

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Royal Papworth Hospital NHS Foundation Trust

A member of Cambridge University Health Partners



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royalpapworth.nhs.uk



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Alternative versions of this leaflet

Large print copies and alternative language versions of this leaflet can be made available on request.

View a digital version of this leaflet by scanning the QR code.



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As a member of Royal Papworth Hospital Foundation Trust, you could have your say on how the organisation is run, now and in the future. You will receive regular information and news from Royal Papworth and get invited to exclusive events. Membership allows you to vote for your representatives on the Council of Governors, talk to your Council of Governor representatives and stand as a governor.



Scan the QR code or head to royalpapworth.nhs.uk/our-hospital/how-we-are-run/foundation-trust-members to find out more.

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