

Moving to an adult transplant unit

Great Ormond Street Hospital (GOSH)
- Papworth Hospital

A patient's guide

Moving into adult care from paediatric care can also be called 'Transition'

'Transition' is a term used by the medical profession to describe the way your care changes from paediatric to adult care in a hospital.

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 this process is not going to be easy for your parents or those who have looked after you up to now. As you take more of the decisions, your parents while probably remaining involved with decisions, will need to accept that they will be taking less responsibility for decision making.

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

Prior to your transition to Papworth Hospital you will be

given the opportunity to be seen jointly with staff from GOSH and Papworth teams. Both teams will discuss with you and your parents the changeover and answer any questions you may have.

You will also have the opportunity to visit Papworth and the Transplant Continuing Care Unit (TCCU) informally before you move from GOSH. You can arrange this by contacting TCCU on 01480 364455.

Transitioned to Papworth

When you have decided you would like to be transitioned to Papworth Hospital a full record of your operation and visits to GOSH will be sent to Papworth prior to your transition and become part of your new notes.

When Papworth receives a formal referral letter about you the consultant in charge looks 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 arrange for Papworth medical and nurses notes to be made up.

Your initial appointment will be sent out by TCCU with 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 to both the patient and the Transplant Unit.

Where is Papworth?

Papworth Hospital is in the village of Papworth Everard. You will find us along the A1198 which is approximately 7 miles south of Huntingdon and 12 miles west of Cambridge. (See map on page 8).

Getting here

By car

There are designated patient car parks within the Hospital grounds. These are pay and display and cost:

- £2.50 for up to three hours
- £3.00 for three to five hours
- £5.00 for up to 24 hours.

If for any reason you need to be admitted for a longer period of time special concessions for car parking are available. Please ask at reception for further information.

These costs may be reviewed. There is also disabled parking, however these spaces are limited.

By bus

Bus services run mainly during the day and less frequently in the evening, so it is advisable to make enquires beforehand.

For services from St Ives and Cambridge contact Whippet Coaches on 01480 463792.

For services from Bedford and St Neots and Cambridge contact Stagecoach on 08706 082608.

By rail

The nearest railway stations are Huntingdon, St Neots, Royston and Cambridge, but you will need to complete your journey by taxi or bus if travelling from any of these stations.

Help with travel costs

You may be entitled to get help from the Hospital with your travel costs if you are receiving certain low-income allowances, eg. Income Support.

If you have any questions regarding which low-income allowances are eligible or any queries about help with your travel costs, please contact the finance officer on 01480 364276.

Accommodation

If you have to travel a long distance you may prefer to travel the day before your appointment. Unfortunately unlike GOSH we do not have hospital accommodation; however we can provide you with an accommodation list close to the hospital. Please contact TCCU on 01480 364455 if you require this.

Your outpatient visits

You will not find your outpatient visits to 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 9:00am and patients are seen on a first come first served basis. On arrival you will be greeted by one of the clinic co-ordinators.

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 your tests you will be seen by the consultant and the transplant nurse and you will be given the opportunity to ask questions. In consultation with the transplant nurse you will be given your next appointment before you leave. You may

choose your appointment to fit in with your work, college or other commitments if necessary. If you like you can arrange your appointment on the same day as your friends providing the clinic is not already too busy.

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 ring 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 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 in-patient admission you will be admitted onto the surgical unit (Mallard Ward) if you have had a heart transplant and to the Chest Medical Unit (CMU) if you are a lung transplant patient. During your in-patient stay you will be expected to self-medicate.

Both ward areas are mixed sex and age but for the most

part each bay of beds is single sex. There are some single rooms, but these rooms are often required for patients who require barrier nursing to prevent spread of infection.

Accommodation is not available for parents, partners or friends. However there are a number of B&B's in the village, which offer rooms at low rates. Please ask for a list should you require accommodation.

Telephone help line

The TCCU run a telephone help line staffed by the transplant nurses 0800-1700 hours Monday-Friday. Out of those hours there is always a transplant doctor on call to answer any questions or concerns that 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 telephone **01480 830541**.

This help line is accessible to all. Parents can ring 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 for yourself with your parent's 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 Papworth we have a patient's 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 ext 4452.

Patients notice board

In TCCU waiting room there is an area where patients, family and friends can display articles of interest and achievements to share with others. Please feel free to hand suitable material to any of

the transplant clinic staff and we will be happy to put it on display.

Transplant Games

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

If you're interested and would like more information please contact our team manager Kevin May on 07952 550232, email: kevinmay1@hotmail.co.uk

Further information

Main Hospital Switchboard: 01480 830541.

Transplant Continuing Care Unit: 01480 364455.

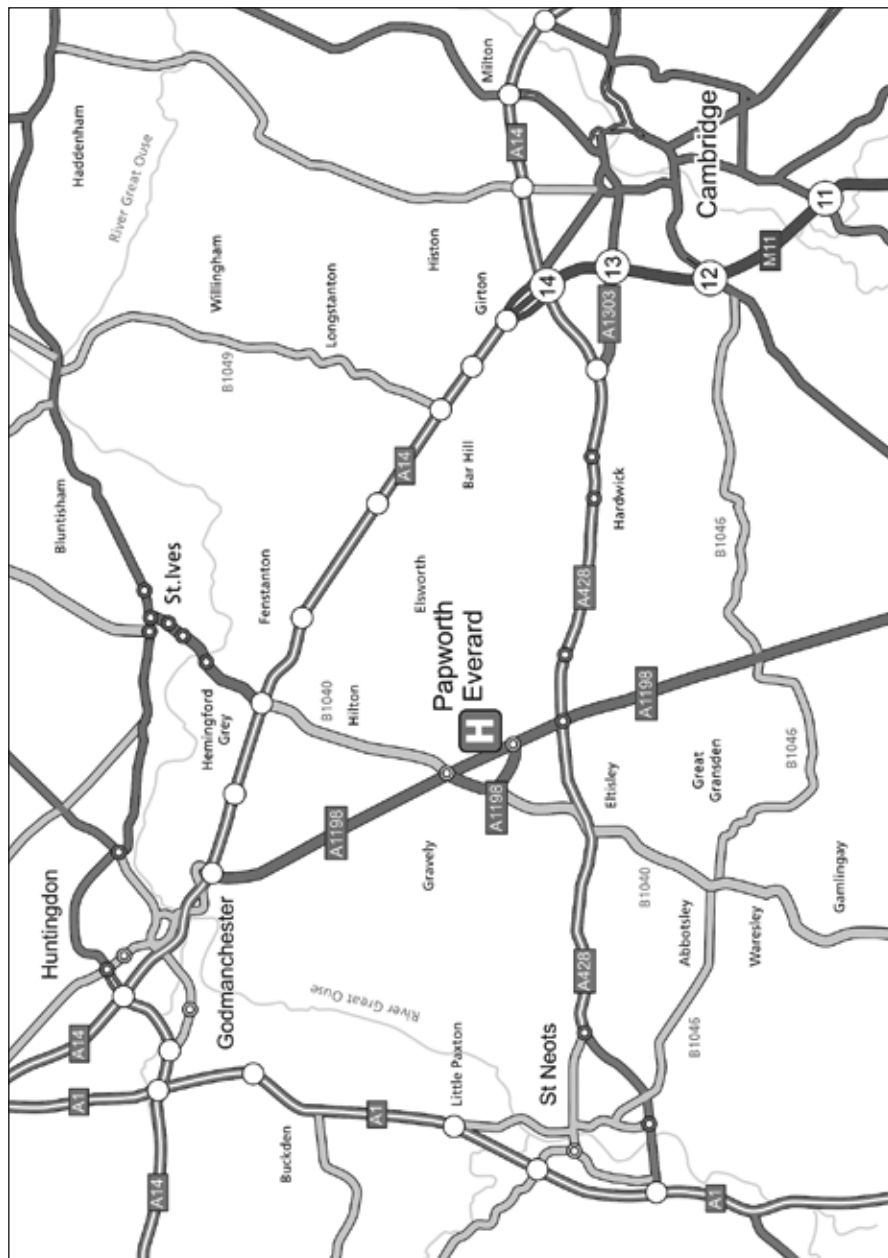
TCCU Fax: 01480 364336

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

Further information regarding the Transplant Unit can be found on the Papworth Hospital NHS Trust web site at www.papworthhospital.nhs.uk

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

Directions to Papworth Hospital



Papworth Hospital NHS Foundation Trust
Papworth Everard, Cambridge, CB23 3RE

Tel: 01480 830541

Fax: 01480 831315

www.papworthhospital.nhs.uk

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