

Moving to an adult congenital heart unit

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 on more of the decisions about your health, your parents will need to accept that they will be taking less responsibility for decision making whilst wanting to remain an active part of this aspect of your life.

This leaflet will try and give you information you require before making a decision to move to the Grown up Congenital Heart (GUCH) service at Papworth.

Prior to transition to Papworth Hospital you will be given the opportunity to be seen jointly with staff from your Paediatric 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 the Papworth GUCH unit informally before you move from Paediatric unit. You can arrange this by contacting the GUCH Specialist Nurse on 01480 830541 Bleep 117

Transition to Papworth

When you have decided you would like to be transitioned to Papworth Hospital a full record of your operation and visits your referring paediatric unit 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 your referring hospital will be asked to send it through prior to your visit.

Your initial appointment will be sent out with details of how to find the GUCH Unit and timings of the visit. The GUCH clinics are held within a clinic room in Papworth Transplant Unit. If the appointment is unsuitable please feel free to contact us and we will find a more suitable date

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 enclosed map)

Getting here

By car

There are designated patient car parks within the hospital grounds. These are pay and display and cost £2 for four hours and £4 for a 24 hour period*.

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

periodically. There is also disabled parking, however these spaces are limited.

**Subject to change*

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 www.go-whippet.co.uk

For services from Bedford and St Neots, Cambridge contact Stage coach on 08706082 608. www.stagecoachbus.com

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 to 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, e.g. 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. We can provide you with an accommodation list close to the hospital. Please contact the unit on 01480 364455 if you require this.

Outpatient visits

You will not find outpatient visits to Papworth Hospital very different to your paediatric clinic and even though you are now attending an adult centre, your parents (if you wish) can come with you to see your consultant with you.

However, many patients choose to take on a more independent role once transition has occurred. 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 within the Transplant Unit and are generally held on Thursdays. We will try and carry out any investigations you may need on the day of your clinic appointment; however this is not always possible

The following tests may need to be carried out during or before 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.

Electrocardiogram (ECG)

This is a painless test we carry out to look at the electrical activity of the heart and takes about five minutes. Small sticky patches called electrodes are put on the arms, legs and chest. These are connected by wires to an ECG recording machine.

Chest X-ray

A chest X-ray allows closer

examination of the heart, lung and chest. The radiographer will ask you to stand with your chest pressed to a photographic plate. You will then be asked to take a deep breath in and hold it. Whilst the radiographer takes the X-ray

Echocardiogram

This is very similar to an ultrasound scan and allows us to look at the structure and get a more detailed picture of your heart. A recorder probe that gives off pulses of ultrasound wave is placed on your chest and the probe then picks the echo waves from various parts of the heart.

Lung function/cardio pulmonary exercise test

Cardiopulmonary exercise testing (CPEX) is a non-invasive method used to assess the performance of the heart and lungs at rest and during exercise. During the test you will be asked to perform mild exercise on an upright bicycle whilst breathing through a mouthpiece. Each breath will be measured to assess how the body is performing. The capacity and strength of the

lungs is measured before and during exercise. The heart tracing (ECG) will also be recorded prior to, during and post exercise.

MRI

This test allows us to look at the structure of the heart and blood vessels in more detail. It takes about one hour. This test is not painful or uncomfortable. You will lie in a short 'tunnel' around which there is a large magnet. Short bursts of magnetic fields and radio waves from the MRI scanner allow images to be created.

Cardiac exercise test

This is an exercise ECG that is recorded while you are walking on a treadmill or an exercise bike. This will allow us to see how your heart works when you are moving about and when your heart has to work harder

Following all your tests you will be seen by the consultant and the clinic nurse and you will be given the opportunity to ask questions (you may want to make a note of these before your visit).

In consultation with the clinic nurse you will be advised of your next appointment before you leave. The frequency of your appointment is assessed on an individual basis and some people may require visits more frequently.

If you do not attend your appointment you will be contacted by one of the 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.

Telephone helpline

The GUCH service run a telephone helpline which is staffed 0800-1700 hours Monday to Friday on 01480 830541 Bleep 117.

Out-of-hours and in emergency situations you will need to contact your GP or your local Accident and Emergency (A&E) Department. They then can contact an oncall doctor via the main hospital switch board Tel 01480 830541. This help line is accessible to all.

Parents can ring and speak with one of the nurses but It should be noted that as your children are now at an adult centre no confidential information would be divulged unless you have requested us to do so. Wherever possible we encourage the patient to make contact for themselves with their parent's knowledge and support.

Inpatient admissions

If you require a routine planned admission you will be admitted onto a surgical/ cardiac ward. All wards areas are mixed sex and age, but 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 and for patients under 19 years of age.

Please note: Papworth Hospital does not have an A&E department so in all emergency situations please call your out of hours GP or 999.

Moving away from home

If you are moving away from home to university or college, it is important to register with the resident GP but we will continue to provide the long term care for you at Papworth.

Social calendar

Somerville Foundation

Supporting young people and adults born with a heart condition.

The Somerville Foundation works with patients born with a heart condition (congenital), providing practical and emotional support, and enabling them to take control of their lives and manage their own heart condition.

www.thesf.org.uk

Teen at Heart

For 13 to 19 year olds across the UK this website is for the latest on how to stay healthy and active. Here you will be able to find out all the news and info about your heart and how to live a healthy fun lifestyle.

www.yheart.net

Patients notice board

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

Telephone numbers

Main hospital switchboard	01480 830541
GUCH nurse	01480 830541 Bleep 117
Transplant Continuing Care/GUCH Unit	01480 364455
TCCU/GUCH fax	01480364336

Further information regarding the GUCH Unit can be found on the Papworth Hospital NHS Trust websites at:

www.papworthhospital.nhs.uk

www.papworthhospital.nhs.uk/transitioning

We have a generic email address but in order to use this facility we will require you to sign a consent form which you will be able to sign at your combined appointment or on your first visit to Papworth Hospital. Therefore until you have signed the required form the preferred method of contact is by telephone. All calls will be returned on the same day if possible.

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

Tel: 01480 830541

Fax: 01480 831315

www.papworthhospital.nhs.uk

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