

Moving to an adult congenital heart disease (ACHD) 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 or legal guardian 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 booklet will try and give you the information you require to understand the transfer of your care to the

Adult Congenital Heart Disease (ACHD) service at Royal Papworth Hospital.

Prior to transfer to Royal Papworth, you will be given the opportunity to be seen jointly with staff from your paediatric and Royal 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 Royal Papworth ACHD Unit informally before you move from your paediatric unit. You can arrange this by contacting the ACHD Specialist Nurses on 01223 639944.

Transfer to Royal Papworth

When your care is transferred to Royal Papworth a full record of your heart conditions, any previous operations and visits to your referring paediatric unit will be sent to us before your first appointment and become part of your new notes.

When Royal Papworth receives a formal referral letter about you, the consultant in charge looks at all the 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 ACHD Unit and the timings of the visit. The ACHD clinics are held within a clinic room in the outpatients department.

If the appointment is unsuitable, please feel free to contact the booking office on 01223 638933 and they will try to find a more suitable date.

Where is Royal Papworth Hospital?

Royal Papworth Hospital is based on the Cambridge Biomedical Campus. You will find us on Papworth Road, Cambridge CB2 0AY.

You can find out further information on how to get to

our hospital by heading to:
royalpapworth.nhs.uk/getting-here

Alternatively you scan this QR code:



If you are unable to access the above, please let a member of the team know.

Outpatient visits

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

However, many patients choose to take on a more independent role once the 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 generally held on Thursdays. On arrival, you need to check in with the reception staff at the outpatients reception desk. We will try and carry out any investigations you may need on the day of your clinic appointment, however, this is not always possible.

Being called for your appointment

When in the waiting area, you will be called for your appointment via a calling screen. These are located throughout the outpatient waiting area, and your name will appear on the screen with the location you need to go to. This includes any additional tests booked for you on the day.

If you do not wish to have your name appear on the screen, please talk to a member of the reception staff when you check in and they can make alternative arrangements.

Facilities and services

Pharmacy

If you are collecting a new medication prescribed for you in the clinic, this will be dispensed by the pharmacy which is located on the ground floor of the hospital.

Wi-Fi

There is free Wi-Fi available throughout the hospital. Please select 'NHS Wi-Fi.' Our acceptable use policy can be found at: <https://royalpapworth.nhs.uk/wifi-aup>

Hospital shop

WHSmith located on the ground floor sells a selection of food, drinks, snacks, confectionary, magazines and more.

Restaurant

The restaurant which is overlooking the duck pond is located on the ground floor. They serve hot and cold meals, sandwiches, baguettes, salads, fruits, and a range of drinks.

Coffee shop

The coffee shop is located on the ground floor and serves Costa coffee, hot and cold drinks and light snacks. There are also self-service Costa coffee machines stationed within WHSmith and the restaurant.

Cashier's office

This is located on the ground floor of the hospital.

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 ACHD specialist nurse in the clinic. They will also talk through lifestyle advice, health promotion, medications, and any other issues you may wish to discuss.

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 a closer examination of the heart, lungs, 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.

Bloods

Routine blood tests may be required on the day of your visit to monitor your heart function and general health.

Echocardiogram

This is an ultrasound scan which is safe, painless and without radiation. It allows us to look at the structure and get more detailed pictures of your heart. You will be asked to lie on both your back and then your left-hand side whilst an echo sonographer uses a handheld probe with gel on it to acquire images of your heart.

Cardiopulmonary exercise test (CPET)

This 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 for about 15 minutes whilst breathing through a mouthpiece.

Each breath will be measured to assess how your body is performing. The capacity and strength of the lungs are measured before and during exercise. The heart tracing (ECG) will also be recorded before, during and after exercise.

The entire exam may take from 45-60 minutes. You may feel tired after the test because you just had a good workout!

Cardiac exercise test

This is an exercise ECG that is recorded while you are walking on a treadmill or an exercise bike. This allows us to see how your heart responds to exercise.

Computed tomography (CT) scan

A CT scan uses x-rays to take pictures of the inside of the body. You will be asked to lie on a flat bed that enters the scanner which looks like a large doughnut.

You may hear a humming noise similar to a washing machine, but the scanner does not touch or hurt you. Most scans are about 10-20 minutes in length and some scans may require contrast into your bloodstream which would need a cannula inserted into your arm.

Magnetic resonance imaging (MRI) scan

This test allows us to look at the structure of the heart and blood vessels in more detail.

It may be as short as 30 minutes but sometimes can last for up to two hours especially if intravenous contrast is needed.

This test is not painful or uncomfortable but loud knocking or banging noises will be heard; you will

be given headphones to reduce the noise.

You will be asked to lie still in a short 'tunnel' around which there is a large magnet. You will hear instructions asking you to hold your breath. Most people manage these fine but if you struggle let the radiographer know and they can either give you longer between pictures or try and reduce the amount of time you have to hold your breath.

Holter monitoring

As irregularities in heart rhythm may not be present all the time, you may be asked to wear a Holter monitor for 24 hours, 72 hours or a whole week.

Electrodes like conventional ECG patches will be attached to your chest. The wires are attached to a digital recorder that is worn on a belt around the waist or a shoulder strap.

This will record your heart's electrical activity continuously throughout various activity levels therefore there is a greater chance of detecting

abnormalities. After returning the monitor, a technician analyses the recording.

Following all of your tests, you will be seen by the ACHD consultant who will review you and discuss all the investigations that have been performed. You will be given the opportunity to talk about your health concerns and ask questions accordingly.

The frequency of your appointment is assessed on an individual basis and some people may require visits more frequently than others. If you do not attend your appointment, you will be contacted by one of the specialist nurses.

Following your clinic visit, you and your GP will receive a copy of your clinic letter.

Telephone and email helpline

The ACHD service runs a telephone helpline 01223 639944 which is staffed Monday-Friday 09:00-17:00.

Out of hours and in emergencies, you will need to

contact your GP or your local accident and emergency (A&E) department. They can then contact an on-call doctor if required via the main hospital switchboard on 01223 638000.

This helpline is accessible to all. Your parents can ring to speak with one of the nurses, but it should be noted that as you are now at an adult centre, no confidential information would be able to be discussed unless you have requested us to do so. Wherever possible we encourage you to make contact for yourself with your parents' knowledge and support.

Specialist nurses are also contactable by e-mail at papworth.achdnurses@nhs.net for any non-urgent queries.

Inpatient admissions

If you require a routine planned admission, you will be admitted to a surgical/cardiac or day ward. All ward areas are mixed sex and age, but each bay of beds is single-sex. Most rooms are single rooms, but these are often required for patients who may require

barrier nursing to prevent the spread of infection and for patients under 19 years of age.

Royal Papworth Hospital does not have an A&E department so in all emergencies 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 and we will continue to provide long-term specialist care for you at Royal Papworth Hospital.

Information and advice

Somerville Heart Foundation

Visit **sfhearts.org.uk** for information and support for young people and adults born with a heart condition.

By signing up, you will have free access to all Somerville Heart Foundation support services and the ACHD community which will give you the power to build a better future.



FOR YOUNG PEOPLE & ADULTS BORN WITH A HEART CONDITION

Somerville
Heart
Foundation



www.sfhearts.org.uk

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Teen at Heart

The British Heart Foundation programme for young people with heart conditions. Visit **yheart.net** to find out about events and read more about growing up with a heart condition and how to live a healthy fun lifestyle.



Understanding your heart: a series of booklets from the British Heart Foundation

Scan the QR codes using your smartphone camera or QR reader to view the booklets.



"Straight from the heart"



Arrhythmias



Aortic Stenosis



Atrial Septal Defect



Coarctation of the Aorta



Hypoplastic left heart syndrome



Implantable cardioverter defibrillator (ICD)



Long QT syndrome



Pulmonary atresia with intact ventricular septum



Pacemakers



Pulmonary stenosis



My heart operation



Transposition of the great arteries



Transition to adult services



Tricuspid atresia



Ventricular septal defect

Patient noticeboard

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.

Useful contact details

Main hospital switchboard: 01223 638000

ACHD specialist nurses helpline: 01223 639944

ACHD secretary: 01223 639785

ACHD outpatient bookings: 01223 638933

ACHD email: papworth.achdnurses@nhs.net

Further information regarding the ACHD Unit can be found on our website: royalpapworth.nhs.uk/our-services/cardiology-services/adult-congenital-heart-disease-achd-unit

Alternatively you scan this QR code:



In order to use our email address listed above, we will require you to sign a consent form. You will be able to do this at your combined appointment or on your first visit to Royal Papworth. 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.

Royal Papworth Hospital NHS Foundation Trust

A member of Cambridge University Health Partners



Papworth Road
Cambridge Biomedical Campus
CB2 0AY



royalpapworth.nhs.uk



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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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