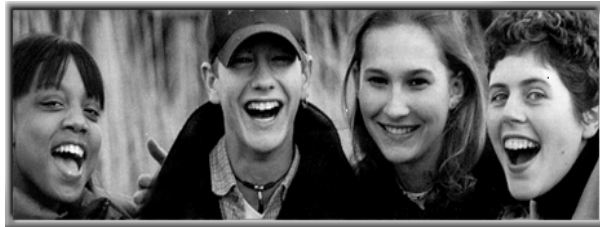


# Grown Up Congenital Heart Clinic (GUCH)



A Guide for Young  
People

## **ABOUT THIS LEAFLET**

This leaflet has been put together to give you an idea of the changes involved in coming to the young persons cardiology clinic, in very different surroundings.

*University Hospital Birmingham (UHB) is based on 2 sites, cardiology outpatients is at Selly Oak Hospital, and cardiac inpatients and investigations are at Queen Elizabeth Hospital. A map for both sites is at the back of this leaflet.*

## **THE CLINIC**

The clinic is situated on the second floor of the Outpatients Department at Selly Oak Hospital.

## **WHY BOTHER?**

The reason that this leaflet has been put together is because research shows that people cope much better with change if information is given in advance. Because you have been attending the Young

Persons Cardiology Clinics at Birmingham Childrens Hospital you should hopefully have some idea of what will happen.

### **DO I HAVE TO GO IN TO SEE THE DOCTOR ON MY OWN ON MY FIRST VISIT?**

No, you don't but it is important to know you can whenever you feel ready to do so. *The doctor will be happy to see you on your own or with your family or a friend.* At the first visit the doctor will ask you a lot of questions. He/she will ask you what you know about your condition, what medicines you are on (if any) and what you plan to do with your life. This will help you build your confidence and develop the ability to take charge of your own healthcare. Also this visit will be the longest as your adult cardiologist needs to get to know you.

### **WILL MY PARENTS/CARERS STILL BE ABLE TO SEE THE DOCTOR IF I GO IN ON MY OWN?**

Yes. Sometimes they find it strange waiting outside for you but they will still have the opportunity to see the doctor if they want to, usually at the end of your visit. Don't forget they have been coming to outpatients with you since you were first diagnosed so may find it hard to "let go".

### **WHAT IF I WANT TO ASK THE DOCTOR SOMETHING I DON'T WANT MY PARENTS TO KNOW ABOUT?**

That's okay. Whatever you say to the doctors is strictly confidential and will not be passed on to your parents or carers without your permission.

### **IS THERE ANYTHING I NEED TO BRING WITH ME?**

Yes! Write down any questions you want to ask in clinic (it is easy to forget them!) as well as a list of your medicines, also bring along your hand held records so it can be updated.

When you arrive your height, weight, oxygen saturations and blood pressure will be measured.

### **WILL ANY INVESTIGATIONS BE DONE WHEN I ATTEND?**

Normally there is an ECG and ECHO technician in the Outpatients department and the Consultant will have reviewed your notes beforehand and will have decided if you need any investigations carried out. However, there aren't the facilities on hand

to carry out Exercise ECG's or 24 hour ECG monitoring and in those circumstances you *would have to attend the Queen Elizabeth site for those tests to be carried out.* (A separate appointment will be sent to you along with directions).

On your first visit you will have a Chest X-ray, ECG *and probably an echo* performed before you see the Doctor so be prepared for a busy visit!

### **WHY DO I HAVE TO MOVE TO THE ADULT SERVICES?**

As you become an adult your healthcare and lifestyle needs will change. The adult service is better at giving you and your family the right care, treatment and support.

### **WHO'S WHO IN CLINIC**

Your Cardiologist....., is responsible for GUCH (Grown Up Congenital Heart) patients.

There are a number of Staff Nurses responsible for running the GUCH clinics and will be able to support you if you have any questions.

There is a GUCH Clinical Nurse Specialist available to discuss your condition and offer

health and lifestyle advice should you need it.

Their contact number is .....

Selly Oak is a teaching hospital and occasionally there are **medical or nursing students** in clinic. You will always be asked if you mind them sitting in on the consultation. If you would rather they didn't please do not hesitate to say so.

### **CAN I CONTACT THE CARDIOLOGY TEAM MYSELF?**

Yes – in fact we encourage it! You will have already been issued with a card with details on it but if you are unsure here is the number to contact.

Your Consultant's secretary can be contacted on **0121 627 2959** or **0121 627 2870** who will be able to put you in touch with your doctor or advise you who you should contact in an emergency.

### **I AM WORRIED ABOUT LEAVING THE CHILDREN'S HOSPITAL. WILL MY ADULT CARDIOLOGIST KNOW ALL ABOUT MY CONDITION AND THE CARE I HAVE HAD?**

Yes. When you move to the adult service all-important information will be sent to your

cardiologist. He /she also continues to work closely with Consultants at the Children's Hospital.

We hope you find the move to the Grown Up Congenital Heart Service a positive experience.

**Further information.**

We hope this information leaflet will help you to get ready for attending the clinic at University Hospital Birmingham.

But when you attend you may still have many questions. Please talk to the people you meet to get more information.

Your G.U.C.H. Cardiologist is

Dr .....

Telephone 0121 627 2959 or 0121 627 2870 and speak to his/her secretary.

We have tried to make this leaflet as clear as possible. If you would like more information

or help, please contact the G.U.C.H. Liaison Nurse or nurse on the cardiac

Information about University Hospital Birmingham can also be found on the Internet.

The Cardiac Unit at Birmingham Children's Hospital has produced this leaflet with help from the University Hospital Birmingham.

### **Data Protection.**

We collect information about you and your diagnosis and treatment. We store it in written records and on computer. We may have to share some of your information with other people and organisations. If you have any questions and / or you do not wish us to share information with others, please talk to the people looking after you or contact the Patient Advice and Liaison Service officer.

### **Taking tissue samples.**

To help find out what is wrong with you or how well the treatment is working, we may need to take tissue samples.

Tissue samples are things like:



- Body fluids, such as blood, urine and saliva.
- Small pieces of skin, small pieces of internal organs or lumps.

You may need many tests. We will never do more tests than needed. But sometimes when we do test a little tissue leftover when we finish. We might use this to:

- Teach staff and students more about people's illnesses and how we find out what is making them ill.
- Do research to try to find out about illnesses (this will only be done if permission is given by our Ethical Committee, whose job it is to look after your interests).
- Check that tests are done properly and give the right results (this is called quality assurance).
- To find out how often people are having similar illnesses throughout the whole country (this is called the National incidence of Disease).

These things help us to know more about cardiac diseases, and make health care better for us all. We very much hope that you will not mind us using your spare tissues like this.

If you want to understand more about why tissues samples may need to be taken, and / or you do not want this

**Please use this space to write down any notes or questions you might have.**