



# GROWN UP CONGENITAL HEART PATIENTS ASSOCIATION



Moving to a GUCH unit  
a guide to adult cardiac care

**Growing up** can be an exciting time, with many changes and opportunities; a first job, going to university, new friends and new relationships. It will also mean that at some point, when you are between the ages of 16 and 18 years, you will transfer from the children's hospital services where you have been seen for your heart condition until now, to an adult hospital services. At this time, you will be encouraged to take control of your own health and to start to make decisions for yourself in relation to the treatment and care you receive. This process is called 'transition'.

Words you will now hear frequently are GUCH, meaning Grown Up Congenital Heart and ACHD, meaning Adult with Congenital Heart Disease. Both are used as abbreviations for adults born with a heart condition.

This leaflet will help you understand the changes in the arrangements for your hospital care.

## First Contact with Adult Services

Everyone growing up with Congenital Heart Disease (CoHD) should be seen by an expert from a specialist centre at least once and receive a written care plan. A care plan is a document that sets out the monitoring and treatments that you will need in the future. It will be written following a full assessment of your condition by your new consultant (specialist doctor). You are likely to be asked about your medical history and any problems you may have. You may well

be given a physical examination as well as the tests such as an X-ray, ECG and/or Echocardiogram (ECHO).

Some hospitals have an actual transition service already set up, where a Paediatric Consultant will see you together with a GUCH Consultant or GUCH Nurse when the hand-over of support begins. You can find a list of consultants at specialist centres on our website.

[www.guch.org.uk](http://www.guch.org.uk) (click on the link 'GUCH Guide' under the article NHS GUCH Guide Advises under the main picture on the home page)

If you find that your new cardiologist's name is not on the list, please ring our helpline 0800 854 759 for advice.

## Ongoing visits to Adult Services

You will most likely be supported by a team of doctors in the adult hospital. Junior doctors will be training in your consultant's team for six months to two years. For this reason you may well see a different doctor at each hospital visit. Other staff in the medical team may include a nurse, psychologist, geneticist, as well as many support staff such as technicians. Medical staff may ask you questions that you have been asked before, or ask you about things that are in your notes already. This can be really irritating but they do need to check that things haven't changed for you since your last appointment and by talking to you they get to know you a bit better and have a fair idea about how much you know about your condition.

At each GUCH specialist centre there is at least one specialist GUCH nurse who is available to offer advice and support. These nurses have had

additional training and they are available to every GUCH patient and their relatives who attend the specialist centre.

## Seeing the Doctor

Even the most confident of people can come away from seeing the doctor having forgotten to ask a question. An idea could be to write down the questions that you want to ask to bring to the consultation. If you don't understand what you have been told at any time, say so and ask them to explain it again. You could suggest they draw a diagram to show what they mean. You could also write down the answer to refer to it when you leave. Sometimes you may feel more comfortable having someone with you when you see the doctor. However, it is also important that you get the opportunity to speak with the doctor alone as both you and they may have questions that are very personal.

Don't be afraid of asking questions about lifestyle issues, e.g. piercings, exercise, alcohol, sex, recreational drugs as you may need to know the effects some of them may have on your health.

GUCH have written a leaflet on "Lifestyle Issues" which gives information on some of the questions you may want to ask including theme park rides, piercings, tattoos and so on. We have also produced a leaflet about pregnancy and contraception. Both are available at GUCH clinics, the Grown Up Congenital Heart Patient Association (GUCH PA) office (01473 252007) and can also be downloaded from our website at [www.guch.org.uk](http://www.guch.org.uk).

## Keeping your Appointments

It is very important that you attend your appointments, which could be every 3 – 6 months, yearly or longer. If for some reason you cannot make a planned appointment, please phone the hospital beforehand and let them know. The doctor will then be able to see someone else instead and you will be given another appointment.

## Between Out-Patient Visits

If you are concerned about any aspect of your health you should see your GP (General Practitioner, your local doctor). You can also phone the GUCH unit and ask to speak with your GUCH Nurse. Tell them who you are and what the problem is and they will be able to advise you or bring your appointment with the team forward. If there is no GUCH Nurse available to you, try contacting your Consultant's secretary who may be able to pass on a message to your care team.

## Your Rights

In the event that you are not happy with your hospital visit you can complain to the Patient Advice and Liaison (PALs) officer who can help you. You can find out the contact details of your PALs officer is through your hospital switchboard or website.

This should not affect your relationship with your Consultant, as they are professionals who are interested in treating you to the best of their ability. You can apply to see your health records and are entitled to see them. This applies even if you are under 16 providing the record holder considers you will be able to understand what they say and mean.

## Personal Health Passport

GUCH PA has produced a pocket-sized booklet for you to keep with you. It allows you or the consultant/doctor/nurse to write down the details of your condition and medication as well as the names of those looking after you, and possibly a contact telephone number. It is very useful in an emergency and helps you explain your condition to others including friends, tutors and dentists. These are free and you will either be given one at your GUCH clinic or can get one direct from the GUCH PA office.

## Medical Records Wallet

It is more likely these days that you will be given a copy of your ECG and sent a copy of the letter your Consultant sends to your GP. It would be sensible to put these in a safe place so you can take them with you in the event of needing to go into hospital for another reason. You may also be asked to take them back with you each time you have a check up. GUCH PA makes available a free medical records wallet to make it easier to know where your documents are. Again, you can get one of these either from your GUCH clinic or from the GUCH PA office.

## Learning more about your own condition

The Grown Up Congenital Heart Patients Association (GUCH PA) has produced this leaflet. We are a charity that supports adults and young people born with a heart condition.

We have information leaflets, a website and a freephone helpline as well as a quarterly newsletter, GUCH News. We also employ a Young

People's Mental Health Worker supported through Comic Relief. Our weekends away and 'outward bound' holiday breaks are great for meeting people with similar conditions. Our message board is a great way to talk to other GUCHs,

Visit us at [www.guch.org.uk](http://www.guch.org.uk).

You can receive regular information from GUCH PA by filling out and returning the form at the end of this leaflet or through our website.

## Contact

Saracen's House, 25 St. Margaret's Green,  
Ipswich, Suffolk IP4 2BN  
Telephone 01473 252007  
Fax 01473 281823  
Helpline 0800 854759  
[www.guch.org.uk](http://www.guch.org.uk)



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[www.guch.org.uk](http://www.guch.org.uk)

email: [info@guch.org.uk](mailto:info@guch.org.uk)

Registered Charity Number 1041866

## Join GUCH Patients Association

I would like to join GUCH PA and receive GUCH News, the Association's Quarterly Newsletter, and be informed of forthcoming events.

Full Name \_\_\_\_\_

Year of birth \_\_\_\_\_

*GUCHs only (for statistical information). Please leave blank if you prefer*

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

Telephone number \_\_\_\_\_

E-mail address \_\_\_\_\_

I am (tick box)

a GUCH

a friend or relative of a GUCH Patient

other

Joining the mailing list is free, but a £15 (or more) voluntary donation would be gratefully received. Cheques should be made payable to GUCH PA and sent along with this form.

I enclose a donation of \_\_\_\_\_

### Gift-aid it

*If you you pay UK income tax or capital gains tax you can make your donation go further. For every £10 we receive which is gift aided we get an extra 28.2% back from the Inland Revenue.*

*If you are able to gift aid then sign below.*

*Please treat all donations to GUCH PA as Gift Aid until I notify you otherwise.*

Signed \_\_\_\_\_

Date \_\_\_\_\_

Secure your details by popping this form into an envelope and post it to us at the address overleaf.