

# Transition to our adult congenital cardiac services

This leaflet explains more about the move from paediatric to adult congenital cardiac services. If you have any questions or concerns, please speak to one of the doctors or nurses caring for you.

## What is transition?

The term 'transition' is how we describe the process of transferring your care from the children's heart service (paediatric cardiology) at the Evelina London Children's Hospital, to the adult congenital heart service at St Thomas' Hospital. 'Congenital' means that your heart problem was present from birth.

We describe transition as a **process** because it happens in stages over several years and involves both the children's team and the adult teams.

## When does transition begin and end?

The transition process can begin when you are 12–13 years old. We hope that you will be ready to go to the adult clinic by the time you are 16 years old, although we understand that not everyone will be ready by then. Some young people may go when they are 17 or 18 years old. All young people must move over to adult services by the time they are 18.

Before you go to the adult clinic you may have worked through the **transition passport**. This is a plan of care which makes sure you have been given all the information you need growing up as a young person with congenital heart disease.

## Transition clinics and information days

When your paediatric (children's) cardiologist thinks you and your family are ready, they may arrange for you to be seen at one of the transition clinics in the Evelina London outpatient department. An adult cardiology consultant, clinical nurse specialist and an echocardiographer will join you in clinic so that you get to meet some of the adult team before your first adult clinic appointment. This also gives the paediatric cardiologist a chance to talk to the adult team about any specific issues related to your care that they may need to know about.

You should also receive an invitation to one of our transition information days. Information days offer an excellent opportunity for both you and your parents to find out more about what having congenital heart disease may mean for you as you get older. It is also a chance to meet other young patients who are going through transition.

## Will I still see the team at Evelina London?

Once you are under the care of the adult service, your clinic visits will be with the adult cardiology consultants and nurses in the North Wing of St Thomas' Hospital. However, we do work closely with our paediatric cardiology colleagues and you may bump in to them in the hospital.

The surgeons and some of the specialists who work in catheter intervention work with both adults and children, so you will still see them if you need to have any further procedures in the future.

## What kind of things will be discussed with me at my first adult clinic visit?

We will discuss:

- what you know about your heart condition – what it is and how it affects you
- what care and treatment you have had and also what you may need in the future
- lifestyle issues, such as going away to university and career options, as well as advice on exercise, alcohol, smoking and family planning.

Many of these things may have already been discussed at a transition clinic or information day. You will be able to ask questions at any time if there are things you want to know more about or things that concern you.

## Who will support me through the transition process?

The paediatric cardiac outreach nurses from Evelina London are available for support and help. When you come for your first visit to the adult service, you will be introduced to the adult congenital nurse specialists. They are also involved with your transition and will support you once you have made the move to adult services. They can be contacted before your first visit if you wish (see telephone numbers below).

## Can my parents still come to clinic with me?

Your parents can come to clinic with you for as long as you want them to, even in adult services. As you get older and become used to attending clinics, you may decide to talk to the doctor by yourself and we would expect you to know more about your own heart condition, rather than relying on your parents to answer questions for you. It is important that we prepare you and your family for your move from being a child patient to being an adult patient.

## Will I be able to see the doctor on my own if I want to?

If you are 16 years old or older, you have the right to see a doctor alone. Until you are 16 years old, your parents have a right to come to clinic with you. However, that does not mean that they have to spend the whole of the consultation in the room with you. You can always have time on your own with the doctor, or you could ask to see the nurse specialist alone.

Anything you discuss with your doctor or nurse will be treated confidentially. This means it will not be discussed with anyone else without your permission.

## Where will I stay if I have to be admitted to hospital?

Once you are 16 years old, you will be admitted to one of the adult cardiology wards located in the East Wing of St Thomas' Hospital. We try to admit all of our patients to Becket Ward and when appropriate we will make every effort to ensure a private side room is available, but this is not guaranteed. There is also a separate dayroom on Becket Ward for our ACHD patients and families. It is not possible for family and friends to stay overnight on the ward, unless in exceptional circumstances. If your family and friends would like to stay, there are onsite hotel-style rooms with shared bathroom facilities available in Gassiot House Lodge.

For more information and prices, please call the accommodation office on 020 7188 0276 (Monday to Friday, 9am to 5pm) or email [stthomas.accommadation@gstt.nhs.uk](mailto:stthomas.accommadation@gstt.nhs.uk).

## What happens if I move away from home when I am older, for example, for work or to go to university?

If you move away it is important that you let us know. Regular check-ups are essential to make sure you stay healthy and if you move away we will need to refer you to a cardiologist near your new home, who can continue to monitor you.

If you go away to university you can still see the team here at St Thomas', as we can schedule your appointments to be during your university holidays. However, it is also important for you to have a good doctor near your university, who knows about your condition so that he/she can help you if you unexpectedly become unwell.

## Useful sources of information

**The Somerville Foundation** (formerly known as **GUCHPA** – Grown-up Congenital Heart Patients' Association)

**t:** 0800 854759 **w:** [www.thesf.org.uk](http://www.thesf.org.uk) **e:** [helpline@thesf.org.uk](mailto:helpline@thesf.org.uk)

**ETC – ECHO Teen Club** – Support and friendship for young people with heart conditions treated at the Evelina London and St. Thomas' Hospitals.

**t:** 07715 208077 **w:** [www.echo-teen-club.org.uk](http://www.echo-teen-club.org.uk) **e:** [tim@echo-evelina.org.uk](mailto:tim@echo-evelina.org.uk)

**Meet@teenheart** – The British Heart Foundation's programme for teenagers living with heart conditions.

**t:** 020 7554 0404 **w:** [www.yheart.net](http://www.yheart.net) **e:** [meetatteenheart@bhf.org](mailto:meetatteenheart@bhf.org)

**facebook:** [www.facebook.com/yheartfan](http://www.facebook.com/yheartfan)

## Contact us

If you have any questions or concerns about the change from paediatric to adult services, you can contact the paediatric cardiac outreach nurses on **020 7188 4546**, or the adult congenital specialist nurses on **020 7188 9712** (Monday to Friday 9am to 5pm).

**[CORE TEXT]:** For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

### Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

**t:** 020 7188 3003 10am to 5pm, Monday to Friday      **e:** [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

### Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS)      **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)  
**t:** 020 7188 3514 (complaints)      **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

### Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch.

**t:** 020 7188 8815      **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

### NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111

### NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

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