Royal Brompton and Harefield Hospitals

Congenital heart disease transition clinic

Helping you move from children’s services to adult services
This leaflet is about your move from the children’s congenital heart disease services to adult services at Royal Brompton and Harefield Hospitals. If you have any questions, ask your nurse at the clinic.
The congenital heart disease transition clinic

The congenital heart disease transition clinic is a clinic that helps you move from children’s services to adult services.

“The transition clinic helped me to understand more about my condition.”

Areeba

What is transition?

Transition is about getting you ready to make the move to adult services, helping you understand what to expect, and making sure your move is as smooth as possible.

Why you need to move to adult services

At the moment, you are cared for in children’s services, and your parent(s)/carer(s) have made decisions about your health and care.

When you become a teenager, there are lots of changes going on in your life. You become more independent, and make more decisions yourself.

Your body also changes when you become a teenager, and then an adult. The doctors and nurses in adult services are experts in caring for adults with heart conditions. They will give you the care you need as you get older.

You will move to adult services around the age of 16. The age you move to adult services isn’t the same for everyone, and depends on the care and support you need.
Why go to the transition clinic?

The transition clinic will help you have a gradual and smooth move to adult services.

You may feel unsure about moving, especially if you have been looked after by children’s services for a long time.

The transition clinic gives you plenty of time to get ready for your move. You will get information and support to help make the move easier.

It is important to go to the transition clinic so you have the care and support you need, and can move to adult services at a time that’s right for you.

We also check that you are OK once you have moved to adult services.

When you go to the transition clinic

You will be invited to the transition clinic when you are about 12 or 13.

The number of appointments you have at the transition clinic depends on how much support you need.

After you move to adult services, you will continue going to the transition clinic every one or two years, until you are about 25. This is to make sure you are adjusting well, and have the support you need.

At the transition clinic

At the clinic you will see a transition nurse. The transition nurse is a clinical specialist nurse who helps young people with congenital heart disease move from children’s to adult services.

Your nurse will explain about moving to adult services.
Your nurse will talk about your heart condition, previous procedures, care and medication. You will learn more about your condition, to help you become more independent.

"The nurse took the time to explain everything. I found it very helpful."

Martin

Your nurse will also talk about other things that might be affected by your heart condition, for example:

- a healthy lifestyle and good dental hygiene
- your feelings and emotions
- exercise and symptoms to look out for
- school/college/university
- career choices
- sexual health
- car and holiday insurance.

The nurse will answer your questions and tell you about support groups for young people with congenital heart disease.

You can talk to your nurse about anything that you are worried about.

The transition nurse will write a transition plan for you, so you know what will happen.

Your appointment will last about one hour, and there will be plenty of time for questions. You can go to the clinic on your own, or with your parent(s)/carer(s).
Going to hospital during transition

Up to the age of 15, when you need treatment and tests, you go to Rose Ward (the children’s ward at Royal Brompton Hospital).

When you are about 16, you will go to Paul Wood Ward for treatment and tests. The timing of your move to adult services depends on your needs.
Adult services

When you go to adult services, you won’t need to explain everything. The doctors in adult services work closely with the doctors in children’s services, and have expert knowledge of congenital heart disease.

Royal Brompton and Harefield NHS Foundation Trust is one of the largest specialist centres for adult congenital heart disease in the world.

The adult ward

The adult ward is called Paul Wood Ward.

The ward is for patients aged 16 or over. Beds are in bays, and you only share your bay with people who are the same sex as you. There are bathrooms, and toilets for men and women, near your bay.

There is wifi, and a room where you can use computers, watch TV and eat your meals.

If you are still at school, the hospital has teachers and a school to help with your education. Ask your transition nurse about the hospital school.

Visiting the adult ward

If you would like to visit Paul Wood Ward, ask your transition nurse.

You can also meet other young people who have moved to adult services, if you’d like to.
Transition days

Transition days are for teenagers with congenital heart disease who are moving from children’s to adult services. Transition days are a good way to get more information and meet other young people with congenital heart disease.

Nurses, doctors and other experts will give advice about diet, exercise, smoking, drugs, alcohol and sexual health.

The transition days are called ‘Rhythmic Beats’, and are held in London. If you’d like to go, ask your transition nurse.

Check-ups and changing address

It is very important to have regular check-ups to look after your health.

If you move away or go to university, you need to register with a local GP. Usually you will still have your check-ups at Royal Brompton and Harefield Hospitals.

As you get older you will also become responsible for making your own appointments.

It is important to tell the transition clinic if you can’t attend an appointment, or if you change address.
Contact us

To find out more about the transition clinic, you or your parent(s)/carer(s) can call the clinic on **020 7351 8764**, Monday to Friday, 9am–5pm.

If you need to change your appointment, please call the transition office on **020 7351 8764** Monday to Friday from 9am–5pm.
If you or your parents/carers have any concerns about the service you receive in hospital, and don’t feel you can speak to those who are looking after you, you can call the Patient Advice and Liaison Service (PALS) Royal Brompton Hospital on: 020 7349 7715. You can also email: pals@rbht.nhs.uk. PALS is a confidential service that provides support and advice to patients, families and carers.
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