

# Cardiac transition service

## Information for patients, parents and guardians

We have written this factsheet to give you and your family more information about our cardiac transition service. It explains what our cardiac transition service is, how we can support you and what to expect as you move from our children's services to our adult services. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to a member of our team.

### What is the cardiac transition service?

Our cardiac transition service is a programme designed to support young people with heart conditions to gradually move from our children's heart services to our adult heart services at Southampton.



### Why do I need this service?

Our cardiac transition service will give you:

- an understanding of your body and heart condition, so that you, and your parents or carers, feel confident that you have the skills to manage your condition more independently.
- information about your heart condition and any surgery you've had or may need in the future.
- the opportunity to get to know the adult team and for the adult team to get to know you.

### When will I move to the adult services?

Everyone is different, but most young people move to our adult services between the ages of 16 and 18, once they have had a chance to meet the adult team. We understand that moving away from a team of doctors and nurses that you have been with for many years can be scary, but hopefully by getting involved in the transition process, you will feel more confident and happier about the move.

## What does the transition process involve?

### Ready Steady Go (RSG)

To support you through this process, we've developed the Ready Steady Go transition programme. The programme is designed to prepare you for your move into adult services. For more information about this programme, please visit: [www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx](http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx)

### Ask 3 Questions

The Ask 3 Questions programme is designed to get you involved in making decisions about your treatment. It encourages you to ask three simple questions when you make a choice about your treatment:

- What are my choices?
- What is good and bad about each choice?
- How do I get support to help me make a decision that is right for me?

We are also really keen to hear about other aspects of your life that are important to you, such as your interests, sports you enjoy and what your hopes are for the future, so we can support you to do these things (where possible).

### Frequently asked questions

We have included some of the questions that young people with a heart condition commonly ask us about below:

- Can I go to theme parks?
- Is it safe to have a body piercing?
- What exercise can I do?
- What contraception can I safely use?
- What career can I choose with my heart condition?
- Can I go to university and still have my hospital appointments locally?
- Can I bungee jump?
- Can I go on a skiing trip?
- Can I go abroad with a pacemaker?
- Can I drive with a heart condition?
- Can my parents still be part of my clinic appointments?
- Can my parents still stay with me during a hospital admission?

### What happens next?

When you are in year 9 (Steady RSG questionnaire), we will invite you to a face-to-face transition clinic (or a virtual transition clinic), so we can talk to you about every day issues, including your GCSE choices and future career options. We will also discuss your treatment plan, including any planned procedures.

When you are in year 11 (Go RSG questionnaire), we will offer you a chance to meet the adult heart service team and have a look around the department.

### Contact us

If you have any questions or concerns (no matter how small), please contact us.

Cardiac transition service team

Telephone: **023 8120 4659**

Email: [paedsCHDtransition@uhs.nhs.uk](mailto:paedsCHDtransition@uhs.nhs.uk)

Website: [www.congenitalheartnetwork.org.uk/transition](http://www.congenitalheartnetwork.org.uk/transition)

These contact details are not for emergencies. In an emergency, call **999** and tell the paramedics that you have a heart condition and are under the care of the children's heart services at Southampton.

We look forward to talking to you soon.

### **Useful links**

We have included some useful websites and support groups below that may help with your move to our adult services.

### **A guide to congenital heart disease**

This website contains lots of useful information, including information about travelling, learning to drive and exercising with a heart condition.

Website: [chd.heartresearch.org.uk](http://chd.heartresearch.org.uk)

### **Teen Heart**

Teen Heart is a support group run by the British Heart Foundation for young people aged between 13 and 18.

Website: [www.bhf.org.uk/.../children-and-young-people/teen-heart-events](http://www.bhf.org.uk/.../children-and-young-people/teen-heart-events)

### **Youth Zone**

Youth Zone has been created for young people aged between 11 and 16 as part of the Little Heart Matters national support group. The group is run by a youth leader, and offers advice and support to young people with single ventricle type conditions. Once you turn 16, the youth leader can offer you one-to-one support.

Website: [www.lhm.org.uk/youth-zone](http://www.lhm.org.uk/youth-zone)

### **The Somerville Foundation**

The Somerville Foundation provides support for young people and adults born with heart disease. The charity provides emotional support, as well as useful information on work, finance and travel.

Website: [thesf.org.uk](http://thesf.org.uk)

### **Hannah Phillips' podcast**

Hannah Phillips has a congenital heart condition and has shared her experiences to help other young people living with a congenital heart condition. She also has her own podcast, where you can share your own experiences and thoughts with her.

Podcast: [www.spreaker.com/show/sunshine-sessions](http://www.spreaker.com/show/sunshine-sessions)

Instagram: [hannah.pips](https://www.instagram.com/hannah.pips)

Twitter: [@Hannahpipz](https://twitter.com/Hannahpipz)

## Useful apps

### Heartpedia

Heartpedia allows you to interact with 3D models of heart anomalies and defects, which can help you to understand more about your heart condition.



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[www.uhs.nhs.uk/childrenshospital](http://www.uhs.nhs.uk/childrenshospital)

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