

Transition

Information for parents of young
people with congenital heart disease



What is transition?

It is about getting ready to move from the children's to the adult congenital heart service. This usually happens when your son or daughter is around 16 years old.

Why think about it now?

This is just one of the many changes that are happening in your teenager's life as they become an adult. The more you all understand about what will happen, the easier it will be. Becoming an adult means taking responsibility for your own healthcare. You will have been making most of the decisions about your son or daughter's heart condition so far. During transition we can help them, alongside you, to become more independent and to understand their heart condition better.

Why is there a need to move to the adult services?

The adult service is better at giving the right care, treatment and support as your teenager becomes an adult.

Getting Ready

We can help you get ready to move to adults by:

- Helping your son or daughter to understand about their heart condition and any medications they are taking
- Discussing contraception and pregnancy risks as these may have implications to your child's heart condition in the future
- Make sure that you know who to contact if you have any questions or concerns
- Talk to your son or daughter about the importance of a healthy lifestyle including the importance of exercise

- Give your son or daughter information about support groups for young people with congenital heart disease
- Support you through this change. It can be really hard to think about 'letting go' after taking full responsibility for your child's health care, in many cases since they were born. The children's and adult teams work closely together and will try to make transition as smooth as possible
- Helping your son or daughter to understand the need for life-long care so they don't get lost to follow-up

Transition Evenings

These are held regularly and are an opportunity to find out more about the adult service and meet some of the staff in an informal atmosphere. Look on the website for the dates.

Top Tips

- Don't worry, you will still be very involved in your son or daughter's care during this time
- Talk to them about transition and how they feel about it
- Encourage your son or daughter to find out more about their heart condition
- Come to one of the Transition Evenings and meet the Adult Nurse Specialists and other members of the team. Look on the website for the dates
- Get in touch if you have any questions

Information and advice

Cardiac Nurse Specialists

Tel: 0113 392 5467

ccns.lgi@nhs.net

www.leedscongenitalhearts.com

Meet@teenheart

The BHF programme for young people with heart conditions. Visit yheart.net to find out about events and read more about growing up with a heart condition.

Somerville Foundation

thesf.org.uk

Information and support for young people and adults with congenital heart disease.