

Transition

Information for 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 you are around 16 years old.

Why do I need to think about it now?

So you can prepare and be ready when it is time to move on. The more you understand about what will happen, the easier it will be for you.

Becoming an adult means taking responsibility for your own healthcare. Your family will probably have been making most of the decisions about your heart condition so far.

During transition we can help you, along with your family, to become more independent and to understand your heart condition better.

Why do I need to move to the adult services?

The adult service is better at giving you and your family the right care, treatment and support as you grow up.

Getting Ready

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

- Helping you to understand about your heart condition and any medications that you are taking
- Discussing contraception and pregnancy as this may have implications for you and your heart condition
- Making sure that you know who to contact if you have any questions or worries
- Talking to you about having a healthy lifestyle and the importance of exercise

- Giving you information about support groups for young people with congenital heart disease
- Talking to you about school and your future career and whether your heart condition may affect this.
- Understanding why you need to be seen as an adult and you continue to have regular check-ups throughout your life



Top Tips

- Your family will still be involved in your care during this time and be there for support; talk to them about how you are feeling
- Remember this change may be difficult for your parents, ask them about how they are feeling too
- If there is something that you don't understand or want to know more about, just ask, don't be embarrassed
- Write questions down as you think of them and bring them to clinic so you will remember to ask them
- Come to one of the Transition Evenings and meet the Adult Nurse Specialists and other members of the team. Look on the website or on the Leeds Congenital Facebook site for the dates
- When you are ready, think about coming into part of your clinic appointment on your own.

Where to get more information and advice



Cardiac Nurse Specialists

Tel: 0113 392 5467

ccns.lgi@nhs.net

www.leedscongenitalhearts.com and look at the teen section



Facebook group for young people aged 13 to 18 years, email ccns.lgi@nhs.net for details

Meet@teenheart

The British Heart Foundation 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