

Getting ready to move to the adult service

Information for young people with
congenital heart disease and their
families



leeds children's
hospital

caring about children

LEEDS CONGENITAL
HEARTS

This leaflet aims to give you and your parents/ carers some information about what to expect during the process of transitioning from children's to adult services.

What is transition?

We use the term transition to describe the process of moving from the children's service 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.

What happens?

In the year before your first adult appointment, you will be invited to a transition information session which is held virtually. This is an opportunity to meet some of the adult team and they will talk to you about what to expect in the adult service. These run twice a year and we would encourage you to attend.

If you have a more complex heart condition you will be invited to a virtual 1:1 session with one of the adult congenital heart nurse specialists.

If you are not invited to one of these but think you would find it useful, maybe because you are particularly worried or you have other medical problems, please let the adult nurse specialists know and they can arrange something with you.

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.
- When you are ready, think about coming into part of your clinic appointment on your own.

Tips for parents/carers

- You will have been making most of the decisions about your child's care so far. During transition we can help them, alongside you, to become more independent and to understand their heart condition better.
- It can be really hard to think about 'letting go' and you may worry about the transition process. The children's and adult teams work closely together and will try to make the transition as smooth as possible.

- Encouraging your child to start making health related decisions for themselves will help to ensure they take responsibility as an adult.
- Some young adults get 'lost to follow-up' in the transition process. We would like to work with you so that this doesn't happen.
- If you or your child would like to read a bit more about transition and ways in which you can promote some independence, please go to www.readysteadygo.net and look at the information sheets and questionnaires.
- Please do get in touch with the children's or adult nursing teams with any questions.

Where to get more information and advice

Children's Cardiac Nurse Specialists

Telephone: 0113 392 5467

Email: ccns.lgi@nhs.net

Adult Congenital Heart Nurse Specialists

Telephone: 0113 392 8154

Email: leedsth-tr.achdnurse@nhs.net

Web: www.leedscongenitalhearts.com
and look at the teen section



Join our Facebook Group Leeds Congenital Heart Unit

Teen Heart

Teen Heart is a British Heart Foundation Support Group for people aged 13-18 with a heart condition. By joining you can meet other young people with similar experiences. Sign up for free at yheart.net

The Somerville Heart Foundation

Web: <https://sfhearts.org.uk/>

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



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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