

# Moving On

## Patient Leaflet



# Introduction

**Moving on** from the children's heart service to the adult congenital heart service is an important time in your life.

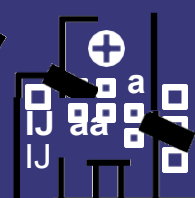
It is a time when you become more involved in dealing with your own heart problem and gradually become more responsible for your own health.

## What will happen?



From the age of thirteen onwards (when you are in year 9 at school) you will be invited to come to a young persons' clinic.

These are held in the outpatient departments at the Royal Manchester Children's Hospital and Alder Hey Children's Hospital in Liverpool.



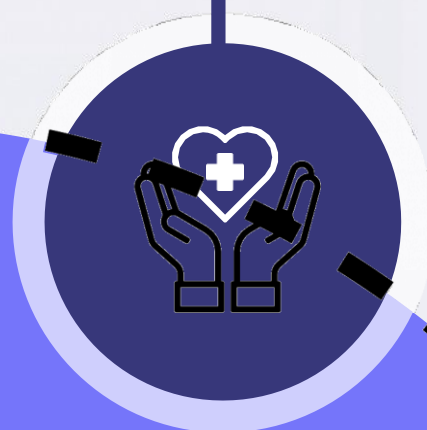
This leaflet is to help you understand this process and how we support young people growing up with a heart problem.



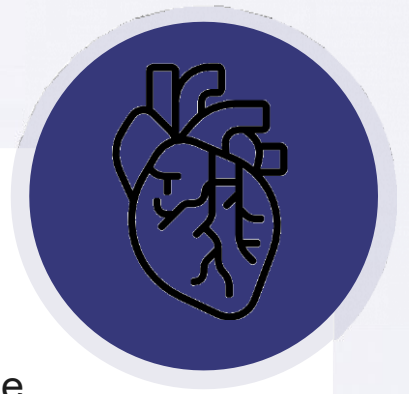
The more you know about your heart condition and how to take care of yourself, the more prepared you will be when it is time to move on to the adult service.



The young person's clinic will help you to become more confident and will help you understand your heart condition.



# Who will help me?



## Your heart doctor will refer you to the Young Person's Clinic.

This service is run by specialist nurses. They specialise in looking after young people who have been born with a heart problem. They will arrange to see you in this clinic. They will be as flexible as possible to avoid you missing too much time from school.



These appointments may be via a video link so that you don't have to travel to the appointment.



You may also be invited to a group appointment where several young people will be seen together.



You will be given information about your heart condition to keep.



You may find it helpful to bring this with you each time you come to clinic.



# Who will help me?

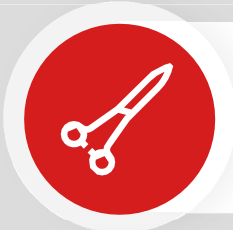


This appointment will be informal and is for you.

You will be asked to fill in a questionnaire to help the specialist nurse talk to you about the things that matter to you. These conversations will happen slowly and over time they will talk to you about the following:



Your heart condition using pictures to help explain it to you.



Explain any operations or procedures you may have had when you were growing up.



Talk to you about any medicines you are taking and why you need to take them.



How to keep yourself healthy including the importance of keeping active.



How to find teenage friendly information on the internet.



Issues around growing up with a congenital heart problem.



Going to high school, university and career choices.



The effects of alcohol, smoking and recreational drugs on your heart.



When you are ready, the nurse will talk to you about relationships and having sex and will include information about contraception and pregnancy



How to find help if you are feeling worried, sad, anxious or angry about your heart problem and how it affects you



What to expect when you transfer your care to the adult congenital heart service



The adult specialist nurses run a private Facebook page called “NWACH Support Group” that you can consider joining once you turn 18 years of age.

# Will I see my usual heart doctor and nurses?

**You will still see your heart doctor as normal in the Children's Hospital.**

The Young Person's (YP) Specialist Nurse will see you as well as the doctors and nurses you usually see. You will also be able to meet the adult team before your transfer your care.

# Can I see the nurse on my own?

**Yes, it is always possible to see the nurse on your own.**

You could start the appointment with someone else in the room to support you. This might be your Mum, Dad or carer but it could also be your friend or someone you trust. As you get older and are used to attending these clinics you may want to meet with the nurse on your own.

This will be up to you to decide. An important part of this process is supporting and preparing your whole family for your move from children to adult services.





# How will my care be handed over to adult services?

There are two ways in which your care may be handed over to adult services:

## Hand over Clinic

You may be invited to a “Hand Over” clinic – where your care is handed over to the adult service in person. In this clinic you will meet the adult team as well as the team from the children’s hospital.

## Direct Transfer

Your heart doctor may send a letter to one of the adult heart doctors and ask them to take over your care.

## Who will support you?

The (YP) Specialist Nurse will be there to support you. They will make sure that you are settled in the adult service and will hand your care over to an Adult Congenital Heart (ACHD) Specialist Nurse who will continue to help you.





## When will I stop going to the Young Person's Clinic?

Different people are ready to move on at different times.

Some people are ready to move to adult services at 16 years of age and some need to wait until they are 18 years of age. You may only need to come once or twice, or you may need to come many times. The (YP) Specialist Nurse will work with you to agree when you are ready to move on to adult services.

# 'Hand Over' Clinic



## What is the 'Hand Over' Clinic like?

Not everyone needs to attend this clinic. This is a clinic to hand over your care to the adult team in person. It is helpful if you have a heart condition that is very complicated. If your heart condition is very simple you may not need to attend this clinic.

You may see the following people in this 'Hand Over' clinic:



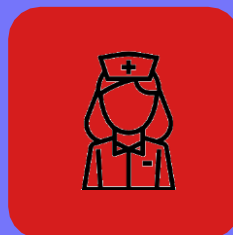
Your parents  
or carers



A friend or  
someone  
you trust



Your Heart  
Doctor from  
the children's  
hospital



The Young  
Persons (VP)  
Specialist  
Nurse



The Adult  
Congenital  
Heart (ACHD)  
Doctor



The Adult  
Congenital  
Heart (ACHD)  
Specialist  
Nurse



# What is the 'Hand Over' clinic like?

At this clinic your heart doctor and nurse from the children's hospital will transfer your care over to the adult congenital heart team (ACHD).

During this clinic they will:

- + Talk to you about your heart problem and how you will be looked after in the adult hospital.
- + You will be given the contact details of the adult team.
- + Your parents or carers will have time to ask any questions they may have as well.
- + Tell you who will look after you and which hospital you will receive your care.
- + You will be able to ask any questions you might have.

# What happens if I don't go to the 'Hand Over' clinic?

Your heart doctor will write to the adult team and ask them to take over your care. This is called a direct transfer.

You will receive the same support and information from the Young Person's (YP) Specialist Nurse. Your care will only be transferred to adult services when you both agree that it is the right time. This will be sometime between the ages of 16 and 18 years of age. The (YP) Specialist Nurse will continue to support you until you have settled into your adult care. You will be able to meet the adult team before your care is moved and you will be told how you can contact them.





## What happens if I move or go away to university when I get older?

The most important way of looking after your health is to have regular check-ups. If you change address or go away to university the Specialist Nurses will make sure that your care carries on as normal whilst you are away at University.



## How can I expect to be treated?

You will always be treated equally and with respect. The staff will do everything to ensure that you feel comfortable. They may check with you what name you would like to use and how you would like to be addressed.



## Who has helped write this leaflet?

Members of the Cardiac Youth Forum called "hearts4teens" helped write this information leaflet.

hearts4teens



# Patient Support Groups for Young People with Congenital Heart Disease



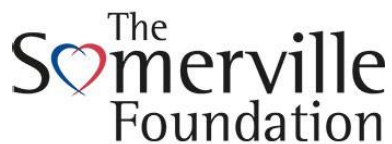
🌐 **Teen Heart** | Aged 13-18 years

<https://www.bhf.org.uk/information-support/heart-matters-magazine/my-story/young-people-and-heart-problems>



☎️ 0151 254 3333

👥 [\(3\) N-WACH Support Group](#)



☎️ 0800 854 759

[www.sfhearts.org.uk](http://www.sfhearts.org.uk)

✉️ [info@sfhearts.org.uk](mailto:info@sfhearts.org.uk)



☎️ 01706 221 988

<https://heartchild.info/web/>

✉️ [information@heartchild.info](mailto:information@heartchild.info)



☎️ 0121 455 8982

<https://www.lhm.org.uk/youth-zone/>

## Other Useful Links



☎ 0151 252 5291

🌐 [Congenital heart network - Alder Hey Children's Hospital Trust](#)

1-



🌐 [www.northwestchdnetwork.nhs.uk/](http://www.northwestchdnetwork.nhs.uk/)

✉ [northwestchdnetwork@alderhey.nhs.uk](mailto:northwestchdnetwork@alderhey.nhs.uk)



☎ 0161 701 0664

🌐 <https://mft.nhs.uk/>

You may wish to contact the specialist nurses during this time. Please use the numbers below:

YP Specialist Nurses at Alder Hey:

☎ Help Line: 0151 252 5291

YP Specialist Nurses at Manchester Children's Hospital:

☎ Help Line: 0161 701 0664

ACHD Specialist Nurses (there is one number for adults regardless of where your care has been transferred to)

☎ Help Line: 0151 254 3333



📍 Alder Hey Children's Hospital, Eaton Road, Liverpool, L12 2AP

✉️ [northwestchdnetwork@alderhey.nhs.uk](mailto:northwestchdnetwork@alderhey.nhs.uk) 🌐 [www.northwestchdnetwork.nhs.uk](http://www.northwestchdnetwork.nhs.uk)