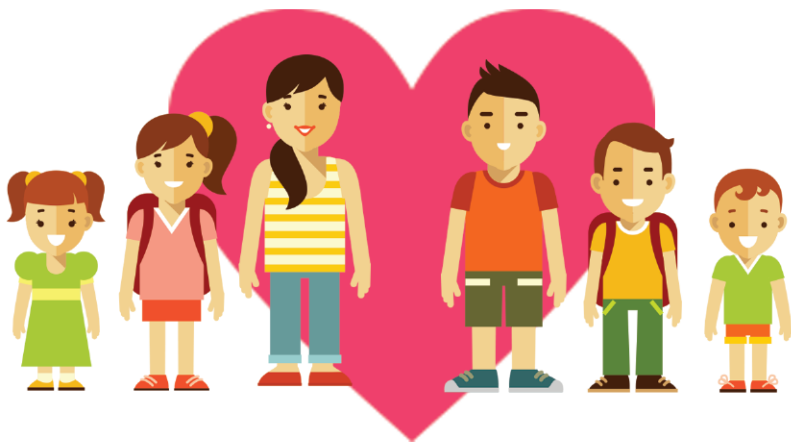


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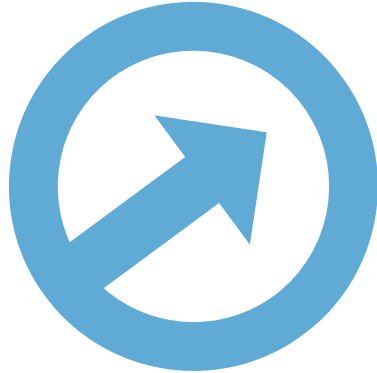


transition?

Getting ready to move on to adult services

Information for teens and young adults





What is transition?

Transition is the term used to describe the process of planning, preparing and moving on from children's cardiology to the adult cardiology services. Transition is a gradual process in which you will become more involved in dealing with your congenital heart condition and more responsible for your own health. 'Congenital' means that your problem has been present since birth.

This process will take place over a number of years, involving the doctors and nurses from both the children's and adult teams.

When will the transition process start and finish?

The transition process will start when you are around 12 years old.

Most young people move on to the adult hospital when they are 15, although not everyone will be ready to move to the adult hospital at this stage.

You, your parents, doctors and nurses from both children's and the Adult Congenital Heart Disease (ACHD) Team will assist you through this process.

Most young people move over to the adult hospital by the time they are 16 years old.



Why do I need to move on?

As you grow into a young adult, the ACHD Team will be best placed to care for your needs. The doctors and nurses in children's hospital and Clark Clinic are experts in caring for babies, children and younger teenagers. The ACHD team are the experts in caring for teenagers and adults living with congenital heart disease. By the time you are at the end of the transition process, you may feel that you have grown out of Clark Clinic and the children's hospital and be glad to move on to a more grown-up environment.

The thought of moving to a new hospital and leaving everyone that you have got to know over the years can be difficult. But we know from experience that it is a good idea to think of this change as a sign that you are growing up and moving on with your life. Some of the doctors from the children's hospital form part of the ACHD Team.



Who can I talk about my transition?

It is natural that you will have many questions and concerns about your transition. You will be able to speak with Clinical Nurse Specialist regarding anything that is bothering you about growing up and moving over to the care of ACHD Team. They will be able to answer your questions, give you information, offer support and advice, organise things and help you to get ready for the move.


Questions you may want to ask might include

- What is the plan for my transition?
- When am I moving to adult services?
- Who is responsible for organising my transition?
- What is different about the adult health care service?
- Can I meet the Adult Congenital Heart Disease Team before I leave Children's?
- Can I visit the adult outpatients and ward to look around?
- Are there other young people who I can talk to about moving to adult services?
- Are there other young people who have already moved to my adult service?



What else can I do to get ready?

It will be helpful for you to practise doing the following things to help prepare you for adult care.

- Learn about your conditions and medications
 - Practise asking and answering questions during ward rounds and clinic appointments
 - Try to take some responsibility for remembering what your medicines are called, what they are for, how much to take and when to take them
 - Learn how to reorder your medication
 - Practise arranging appointments with your Consultant, GP, Physiotherapist or Dietician
 - Keep important phone numbers and appointment dates in your mobile phone, calendar or diary
 - When you agree to treatment plans, make sure that you follow them properly
 - Consider spending time without your parents for part of clinic appointments
 - Find out any changes in your condition that mean you should get urgent help
 - Find out who to contact in an emergency
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How will the adult clinic be different?

There will be a number of difference, the first being the adult clinic is held in the Main Royal Victoria Hospital – Level 2, Dept 2C. The process will be similar to that of Children’s in that you will have some investigations which could include an ECG and/or an Echocardiogram. There after you will be meet with members of the ACHD Team, this will normally be your Cardiologist and possibly the Clinical Nurse Specialist.

One of the main differences between the children’s and adult health services is the amount of independence you will be given. This means that you will need to learn about your condition, so that you can be involved in your care and make decisions for yourself. Your parents or guardian can still come with you to the clinic, although as you get older and become used to attending appointments you may decide to talk to you doctor yourself and there is nothing wrong with developing this independence.




What will be discussed at the adult clinic?

During appointments at the clinic the ACHD Team will spend more time talking to you, rather than your parents. The following are topics which are likely to be discussed:

- What you know about your heart condition and how it affects you. Although this can be scary, it is also good to have more control over your health and the care you are given
- What care and medicines/treatments you have had, and what you might need in the future
- Any further investigations your doctor might feel is necessary. This could include CT Scan, MRI Scan or Cardiac Catheterisation. The team will make sure that you understand everything that might be involved.
- Lifestyle concerns, such as going away to University and career options, exercise, smoking, alcohol and family planning.

Lots of adults take family members or friends along to appointments for support. If you go into an appointment on your own, you can still ask your parents for advice on what questions to ask beforehand. It can sometimes be useful to bring a written list of your questions with you to appointments.



Where will I stay if I am admitted to hospital?

Once you are 15 Years old you will no longer be admitted to Clark Clinic. You will be admitted to one of the adult cardiology wards which are located on Level 5 of the Main Royal Hospital. Every effort is made to provide ACHD patients with a side ward, however this is not guaranteed. It is possible for an adult to stay with you overnight, this would be encouraged until you are 18 years of age. BraveheartsNI & Heartbeat NI have purchased two chair beds for comfort of anyone staying. They have also bought a Media cabinet which includes a PS4 with a selection of games and DVDs and iPads to help keep you entertained during your stay, you will need to ask your Clinical Nurse Specialist for these. There is free WiFi in the main hospital.



What happens if I go to University outside of Northern Ireland?

It is essential that you let the ACHD Team know if you are moving away. You will still need to continue to have regular check ups to ensure you stay healthy. Appointments can still be made during holiday times. It may also be necessary to refer you to a Cardiologist nearer to where you are living. You must also ensure that you get registered with a GP near to where you are living, they must be made aware of your condition so they can help should you become ill unexpectedly.



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FOR FAMILIES WHO HAVE CHILDREN WITH HEART CONDITIONS

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