



University Hospitals Bristol
NHS Foundation Trust

Patient information service
Bristol Heart Institute (Zone C)

Parent/carer's guide to the adult congenital heart disease service



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The adult congenital heart disease (ACHD) team are looking forward to meeting your son/daughter when the time comes for their care to be transferred to the adult congenital heart disease service at the Bristol Heart Institute (BHI).

This booklet explains ACHD services at the BHI and what to expect when visiting the hospital. Overall, things will be quite similar to what you have experienced at the Bristol Royal Hospital for Children.

The BHI opened in 2009 and is the specialist surgical centre for ACHD services for the South West and South Wales. The BHI is located in Zone C behind the Bristol Royal Infirmary (BRI). It can be accessed by either walking through the BRI or approaching from behind the BRI via Horfield Road.

The ACHD team

Our ACHD team consists of four consultant cardiologists, three cardiac surgeons and two cardiac radiologists, some of whom also work in the children's hospital.

There are also four clinical nurse specialists.

The nurse specialists provide a point of contact for patients and offer advice and information on:

- Surgical/cardiology queries and general clinical queries
- Transition (transferring from the children's hospital to the adult hospital)
- Pregnancy advice
- End of life support
- Learning disability support
- Psychological support

- Lifestyle advice
- Financial/employment issues.

The nurse specialists provide an advice telephone line and email for clinical queries for patients, their families/carers and allied health professionals. They aim to respond to a telephone or email query within 48 hours.

The nurse specialists provide support for patients when they are admitted into hospital. The nurses will aim to see their patients daily. They support patients and their relatives/carers throughout their stay.

The nurse specialists support outpatient clinics.

Outpatient clinic appointment

When you arrive at the outpatient department, your son/daughter can give the receptionist their details or check in electronically. Sometimes you may have to wait as some patients need more time than others. We encourage young people to bring music, a book or magazine to pass the time. There is also a coffee shop near the outpatient reception.

Your son/daughter will have an electrocardiogram (ECG) and an echocardiogram (echo) during most outpatient appointments. An ECG measures the heart's electrical activity. Sticky electrodes are placed onto the arms, legs and chest and a recording obtained. An echo is an ultrasound of the heart where jelly is applied to the chest. This is used to examine the structure and function of the heart.

A chest X-ray may be needed if the doctor feels it is necessary. These tests are routine and the majority of patients have them on most visits. When having these tests, every effort will be made to protect your son/daughter's dignity. If they would like a chaperone or would prefer a female to perform their test, please ensure they ask and we will try to arrange this.

After the tests have been completed, they will see the doctor who will discuss with your son/daughter how they are feeling. The doctor will explain their condition and discuss relevant lifestyle issues. They will also make a treatment plan with your son/daughter if one is needed.

It is important to make a note of when the doctor would like to see your son/daughter again. This may be in a few months or in a few years. If your son/daughter does not receive an appointment within this time, please call the consultant's secretary (the details will be on your copy of the clinic letter).

It is very important that you support your son/daughter in attending appointments. Sometimes attending appointments can become difficult if they leave the area for university or college or go travelling. Please encourage them to let us know if they are planning to move away or go travelling, to ensure appropriate arrangements are made.

'Going it alone'

Young people vary in how independent they feel in attending their clinic appointment. Some young people feel confident to see the doctor or clinical nurse specialist alone and others prefer a family member or a friend to accompany them.

If they are accompanied, for part of their appointment we would like to see them alone, as there may be issues which they would like to discuss privately. It is important to establish that they themselves have a good understanding about their care and are not relying on parents/carers. Care will be taken to use words and phrases which are easily understood. We know that medical jargon can be confusing.

Writing down any questions they might have before coming to an appointment is recommended.

'Scared and excited'

Some young people have said they feel 'scared and excited' about transitioning from the children's hospital to the BHI. Staff understand young people are often apprehensive and everything will be explained during their visit. No one expects your son/daughter to know everything. They will be given a lot of support as they begin to manage their own healthcare and they will be encouraged to ask lots of questions.

A visit

Some young people find that having a look around the adult hospital helps them to feel confident about their move. You and your son/daughter are very welcome to come and visit the hospital. If you telephone us to arrange a time, we can show you and your family/carers around. Transition evenings provide opportunity to meet the ACHD team and visit the BHI. These are arranged throughout the year.

Being admitted

Our staff are friendly and are used to looking after young people: they will help as much as they can. The accommodation is either a same sex four bedded bay with one bathroom or single rooms with a bathroom. There are menus to choose your meals from. Bedside televisions are free to use. Patients can bring mobile phones, iPods and portable DVD players to pass the time. There is a wireless network available on the wards.

Visiting time is 8.00am to 9.00pm.

We do appreciate this can be a worrying time for you and your family. If your son/daughter has learning difficulties we will discuss each individual admission with you.

Useful websites

We have a website dedicated to ACHD at the BHI

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-heart-institute-clinical-services/adult-congenital-heart-disease/>

British Heart Foundation

www.bhf.org.uk

The Somerville Foundation

www.thesf.org.uk

Youth At Heart - CHD Charity

www.youthatheart.co.uk

We offer support, awareness, and opportunity to teenagers, young adults and their families in Gloucestershire, born with complex congenital heart disease.

Information about heart disease in young people

www.hearts4teens.org.uk

The doctors

Dr Graham Stuart
Secretary: Miriam Sturman **0117 342 6576**

Dr Stephanie Curtis
Secretary: Lisa Curthoys **0117 342 5967**

Dr Mark Turner
Secretary: Edith Taylor **0117 342 6575**

Dr Radwa Bedair
Secretary: Edith Taylor **0117 342 6575**

Dr Demetries Taliotis
Secretary: Lisa Curthoys **0117 342 5967**

Dr Guido Peles
Secretary: Miriam Sturman **0117 342 6576**

The nurse specialists

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Clinical nurse specialist advice telephone line
0117 342 6599

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While under our care, you may be invited to take part in research. To find out more please visit:
www.uhbristol.nhs.uk/research-innovation
or call the research and innovation team on
0117 342 0233.

For access to other patient leaflets and information please go to the following address:

www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/



Hospital Switchboard: 0117 923 0000



Minicom: 0117 934 9869



www.uhbristol.nhs.uk



For an Interpreter or Signer please contact the telephone number on your appointment letter.



For this leaflet in large print, audio or PDF format, please email patientleaflets@uhbristol.nhs.uk

