

Standard Operating Procedure (SOP)

BRISTOL CONGENITAL HEART CENTRE TRANSITION PROCESS

SETTING	Congenital Cardiology – both Bristol Royal Hospital for Children (BRHC) and Bristol Heart Institute (BHI)
FOR STAFF	Medical and Nursing staff working within the congenital heart service
PATIENTS	Patients with chronic heart disease who are >12yrs in age and who are to transfer to adult cardiac services

STANDARD OPERATING PROCEDURE

Transition is the purposeful, planned movement of adolescent and young adults with congenital heart disease from the children's to the adult cardiac services.

Transition versus transfer

Transition and transfer have been used interchangeably in the health service but mean two different things.

Transition can be defined as, "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescent and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems"

Blum R.W. Garrel D. Hadgman C.H et al (1993) Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the society of Adolescent Medicine. J Adol Health: 14 (7); 570-6

General Points About Transition

- The core transition team is made up of paediatric and adult cardiology staff, who work closely together, to support seamless transfer of care from paediatric to adult services for every young person.
- Inpatient clinical psychology support is available to young people and their families in both the children's and adult hospitals.
- The process begins at age 12 years but is flexible and individualised for each young person.
- The young person (and their family) will be involved in the process at every stage and be encouraged to take responsibility for their heart condition as they move towards adulthood.
- Every part of the process will be individually tailored for each young person.
- We have a dedicated team of specialist nurses, who will help to facilitate the transition process for young people, enabling them (and their families) to understand their heart condition, the effect it may have on their health and what they are likely to face in the future.

- At every consultation through adolescence each young person will have his or her management plan reviewed to ensure that it is relevant to their stage of development. When the young person has transferred to the adult services they will be given a verbal care plan which will be updated following each visit to the hospital. Copies of outpatient letters will also be sent to the young person and family.

The Transition Process in the South West and South Wales

FROM THE AGE OF 12 YEARS:

From the age of 12 years young people will be invited to a dedicated transition clinic at the Bristol Royal Hospital for Children (BRHC) this is the start of discussions regarding transfer to the adult services. They will meet with their cardiologist for their routine follow up appointment and see a Cardiac Nurse Specialist for a 1:1 transition consultation. This discussion will routinely include the following topics:

- The young person's heart condition, long-term management and the need for lifelong follow-up
- Medication, purpose, side-effects and compliance
- Lifestyle issues – diet, smoking, alcohol, education and employment, self-advocacy, sexual health (if appropriate), body image, exercise, travel, risk-taking behaviours
- Contraception (if appropriate), pregnancy and inheritance
- Endocarditis prevention, recognition and dental hygiene
- Exercise
- Local/national support groups

The young person will receive a personalised information pack. This will contain written information as follows:

- Information on their personalised team, who they are, and how to contact them
- Cardiac literature (BHF, Somerville Foundation, Meet@TeenHeart, American Heart Association, Children's Heart Federation etc.)
- Health education leaflets
- Lifestyle information
- Endocarditis literature
- Pregnancy and contraception literature (as appropriate)
- Information on the adult cardiac services
- Written information about support organisations

AGES 12 YEARS TO THE TIME OF TRANSFER TO THE ADULT SERVICES:

The young person will continue to be seen for planned follow up in the transition clinics at the BRHC. A 1:1 consultation with the cardiac nurse specialist will take place during each appointment. Written and verbal information will be revisited and developed upon as the maturity of the young person allows and independence will be fostered.

Appropriate written information (where available) will be provided to complex patients or those that require additional input for:

- Special education needs
- Social circumstances
- Psychological needs

The aim of the 1:1 appointments within the transition clinics are to ensure assimilation and retention of information, and aid a smooth transfer to adult services for the young person and their family.

TRANSITION EVENING AT THE BRISTOL HEART INSTITUTE - >15YRS:

The paediatric and adult teams work collaboratively to facilitate transition evenings at the Bristol Heart Institute (BHI) for young people and their families >15yrs who will be transferring to the BHI upon their discharge from adult services. The purpose of this evening is to prepare for the transfer process and to meet the adult team.

These evenings occur every 6 months.

Patients >15yrs of age will be provided with 2 invitations to support attendance where possible.

AGE 16-18YRS:

- Young person and paediatric cardiologist agree that young person is ready to be transferred to adult services.
- The Medway proforma is completed and young person aware of the medical plan.
- Transfer letter sent to adult consultant cardiologist and the clinical nurse specialist team.
- On receipt a copy of the paediatric referral letter, the ACHD nurse specialist sends information and letter from the CNS team welcoming the young person to the adult services. The adult cardiologist receiving the referral sends the young person a similar introductory letter and schedules an appointment in the ACHD young adult clinic.

YOUNG ADULT CLINIC - BHI

- A detailed summary of the patients care and handover of current issues is sent by the paediatric cardiologist to the adult congenital heart disease cardiologist.
- First appointment at BHI will be in the young adult clinic.
- The Young adult clinic is designed for patients from 16-24yrs.
- Once the young person and the team is happy that the patient understands their heart condition and medication and has learned to take responsibility for their own health they are discharged from the YP clinic to the most appropriate adult congenital cardiologist.

FIRST VISIT IN YOUNG PERSONS CLINIC - BHI

Patient is seen by specialist nurse who goes through the following issues:

- Their heart condition, long-term management and the need for lifelong follow-up
- Their medication, purpose, side-effects and compliance
- Lifestyle issues – diet, smoking, alcohol, education and employment, self-advocacy, sex, body image, exercise, travel, risk-taking behaviours
- Contraception, pregnancy, inheritance
- Endocarditis prevention, recognition and dental hygiene; and
- Support groups.

Patient is then seen by young person's cardiologist who goes through the following issues:

- Their heart condition and medication
- Assesses them clinically
- Performs an ECG
- An ECHO is performed/reviewed by the cardiologist – further imaging may be required
- Cardiorespiratory exercise test to be ordered unless trivial defect or contraindication.
- Lifestyle issues touched on briefly
- Further advice given on endocarditis, exercise, travel, inheritance, contraception and pregnancy

If parents are there they should be asked to leave and the patient should be given the opportunity to discuss any further issues which may be private.

The young person is encouraged to understand and to take responsibility for their heart condition and medication.

RELATED DOCUMENTS

NHS England Paediatric Congenital Heart Disease Standards: Level 1 – Specialist Children's Surgical Centres
<https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-Heart-Disease-Standards-Level-1-Specialist-Childrens-Surgical-Centres-Paediatric.pdf>

AUTHORISING BODY

Cardiac Services Clinical Governance Group

QUERIES

Contact Sheena Vernon Ext 26599 / Lisa Patten 28286