



University Hospitals Bristol **NHS**

NHS Foundation Trust

Patient Information Service
St Michael's Hospital

Information for parents expecting a baby with a heart condition



Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.


Above + Beyond 
For Patients. For Health. For Bristol.

Your unborn baby has been diagnosed with a heart problem (congenital heart disease). As parents, this news will have been shocking and frightening. The aim of this leaflet is to give you information to help you understand who the fetal cardiology team are, what their involvement will be during your antenatal journey, and what will happen between diagnosis and the birth of your baby.

The fetal cardiology team

The team consists of:

Fetal cardiology consultants: these expert consultants will diagnose your baby's heart condition, and will monitor your baby's heart through your pregnancy. They will provide you with an explanation of what that condition means for your baby, and the anticipated plan of care for your baby once the child is born.

Fetal cardiology sonographers: these are expert sonographers who will scan your baby and help support you during your appointments.

Cardiac nurse specialists: during your antenatal journey, a cardiac nurse specialist will be available to you for support and advice. They will provide you with information and support. Their role is explained later in this leaflet.

Fetal cardiac administrators: they arrange and coordinate your appointments. They are one of your points of contact, and will be able to facilitate a response to any queries you have.

The fetal cardiology team has strong links with local teams throughout the South West. They will keep your local team fully informed of your baby's scans and of the plan of care for your baby when the child is born. A letter will detail the discussions your fetal cardiology consultant has with you in clinic, and this will be sent to you and all the relevant professionals involved in your care.

Explanation of your baby's heart problem

At diagnosis, your fetal cardiologist will have explained your baby's heart condition. You will have been given a drawing to show you the normal circulation of the heart, and drawings of your baby's heart. Your fetal cardiologist will have explained to you about your baby's heart, and the implications of the heart condition for your baby once the child is born. You will have been given a pack of information which contains:

- contact numbers so that you can contact the team if you have questions
- information booklets which explain your child's heart condition
- Bristol Royal Children's Hospital booklets, which will give you information about the different wards your baby may visit while in hospital, and information about treatment for your baby's heart condition
- useful websites for support.

From diagnosis to delivery

The fetal cardiology team will want to see you during your pregnancy. This is for a number of reasons:

- to assess how your baby's heart is developing as your pregnancy continues
- after a diagnosis, at around 20 weeks gestation, the fetal cardiology team will want to see you again to assess your baby's heart's development. This usually means coming back a further two or three times to St Michael's for review
- at each appointment your fetal cardiologist will update you about your baby's heart, and will tell you when they would like to see you and assess your baby again

- the fetal cardiology team will provide you with information to help prepare you for when your baby is born
- to give you the opportunity to ask question about your baby, how their heart is progressing and what that means for your baby once they are born
- the fetal cardiology team aims to provide you with support throughout your antenatal journey.

You should carry on seeing your local team.

You should attend local antenatal or baby classes if you want to.

Preparing for your baby's birth

Your fetal cardiology consultant will tell you where your baby will need to be delivered.

For babies that need to be delivered in Bristol at St Michael's Hospital:

- at your 32 week gestation appointment, you will see the fetal cardiology team and your local team
- at this appointment, the fetal cardiology team will confirm the plan for your baby once it is born
- your local team will plan your delivery
- vaginal delivery is almost always possible for babies with CHD except where there is a maternal reason
- if you live outside Bristol, this will mean delivering at about 38 weeks' gestation. Your local team will plan this with you
- if you live in Bristol, you may be able to await spontaneous labour, but again your local team will plan this with you at

your 32 week appointment.

If your baby can be delivered at your local hospital:

- the plan of care for your baby will be outlined in your clinic letter, which will be sent to your local team and you
- your local team will plan your delivery with you.

Wards

During your antenatal visits, you will be given a tour and information booklets on the different wards your baby will visit before they will be discharged home:

Neonatal intensive care unit (NICU)

This is where your baby will go soon after birth for monitoring, IV line insertion, drug infusion (if required) and assessment by a cardiologist and neonatologist. Your baby will be admitted into the intensive care area of NICU so they can receive the appropriate level of care. The children's hospital booklet on NICU in your pack will provide you with more information.

Paediatric intensive care unit (PICU)

This is where your baby will go after cardiac surgery. Sometimes your baby will be admitted into PICU from NICU in readiness for surgery. On PICU, your baby will be nursed one-to-one, or one-to-two, depending on the level of care they require. Following cardiac surgery, there will be lots of equipment attached to your baby to help us monitor and give appropriate care. The day of surgery and the equipment we use is discussed in the booklet 'Ward 32 – cardiac surgery'.

Ward 32 / high dependency unit

This is the cardiac ward that contains the cardiac high dependency unit (HDU). Your baby may transfer into the HDU area of ward 32 before surgery, and will transfer back from PICU to HDU before going to the ward area of ward 32, depending on the level of care they need. In the HDU area, there is one nurse to every two patients, and one nurse to every three patients on the ward area. As your baby improves and before they go home, the cardiac team, nurses, doctors and cardiac nurse specialists will support you and answer any questions you may have. On discharge, you will be given a booklet informing you about what signs and symptoms to look out for and who to contact if you have questions.

Length of stay

Your baby's length of stay in hospital will be discussed with you. If your baby requires surgery in the first week of life, then it would be expected that your baby will be an inpatient for a number of weeks. The length of stay can be variable.

Cardiac nurse specialist (CNS)

The CNS will discuss with you and provide you with information about your baby's heart condition and support groups. They will also provide you with information about being in hospital, from accommodation to parking to what to bring to hospital for your baby. They can also refer you for financial support and psychological support.

If your baby is being born at St Michael's hospital, the CNS team will continue their involvement with you from diagnosis, throughout your baby's stay in hospital and once you are home. They will continue to support you throughout your child's life and can be contacted via the numbers contained in the CNS leaflet. If you have concerns once discharged, please contact the team for support.

If you are delivering in your local hospital, the CNS team are available to support you over the telephone, and you will be provided with their contact details. Any of the CNS team can help you but each member of the team has specific consultants.

- Cathy Harrington is linked to Dr Tulloh and Dr Tometzki.
- Lisa Patten is linked to Dr Hayes and Dr Forsey.
- Jess Hughes is linked to Dr Rob Martin and Dr Bev Tsai Goodman.
- Diane Barlow is linked to Dr Walsh and Dr Stuart.

Remember however that your midwife, health visitor, GP and local paediatrician can be supportive and help you initially as well.

Who will be my baby's doctor

Each week there is a consultant cardiologist on service. This means that each week there is a consultant who is responsible for patients staying in the hospital.

If you live in Bristol, the consultant who is on service that week will become your baby's consultant. If you live outside Bristol, then the cardiology consultant on service will be responsible for your baby's management while in hospital. However, when your baby is discharged, the cardiology consultant who comes to your local hospital will become your consultant.

The cardiology consultants each have a geographical area where they do outreach clinics. So, after your baby is discharged, you may need to come to Bristol for assessment, but usually you can be seen in your local hospital by the consultant cardiologist for that area, and the paediatrician with specialist cardiology knowledge for that hospital. Each consultant has a named CNS. Your baby will be allocated a consultant cardiologist and a CNS.

Geographical links:

- Truro: Dr Hayes
- Torbay: Dr Tometzki
- Exeter: Dr Martin
- Taunton: Dr Walsh
- Plymouth: Dr Hayes and Dr Jon Forsey
- Gloucester and Cheltenham: Dr Tulloh
- Barnstaple: Dr Tsai-Goodman
- Swindon: Dr Jon Forsey

Useful contacts and websites

Bristol Royal Hospital for Children

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/>

ARC

<http://www.arc-uk.org/>

British Heart Foundation

<http://www.bhf.org.uk/>

Children's Heart Federation

<http://www.chfed.org.uk/>

Heartline

<http://www.heartline.org.uk/>

Down's Syndrome Association

<http://www.downs-syndrome.org.uk/>

Future of Down's

<http://www.futureofdowns.com/>

Max Appeal - 22q del11

http://www.maxappeal.org.uk/knowledge/22q11.2_duplications

Exeter Heart Families

<http://www.exeterheartfamilies.co.uk/>

South West Children's Heart Circle

<http://www.heartcircle.org/>

North Devon Heart Babies

<http://www.ndheartbabies.co.uk/>

Contact a Family

<http://www.cafamily.org.uk/>

Martha Care

<http://www.marthacare.org.uk/>

NHS Choices – pregnancy & baby guide

<http://www.nhs.uk/Conditions/pregnancy-and-baby/pages/pregnancy-and-baby-care.aspx#close>

National Breastfeeding Helpline

Telephone: 0300 100 0212

Fetal cardiology team

Fetal consultants: Dr Bev Tsai Goodman and Dr Jon Forsey

Fetal cardiac sonographers: Joanne Jones and Angie Hobbs

Fetal cardiac nurse specialist: Diane Barlow

Fetal administrator: Adam Cockle

Telephone: 0117 342 5694

Fax: 0117 342 5688

Notes/queries

Please note that if for any reason you would value a second opinion concerning your diagnosis or treatment, you are entirely within your rights to request this.

The first step would usually be to discuss this with the doctor or other lead clinician who is responsible for your care.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking contact **Smokefree Bristol** on **0117 922 2255**.

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, Braille, Audio, or Email, please call the Patient Information Service:
0117 342 3728 / 3725

