University Hospitals Bristol NHS
NHS Foundation Trust

Patient information service
Bristol Royal Hospital for Children

Treatment planning and consent for children and young people with cardiac conditions

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When you have a child with a cardiac condition, there will be times where the medical team will want to make decisions with you about what they believe is the right treatment for your child. How we make decisions and when this will happen may vary depending on your child’s condition and when they were diagnosed.

In this leaflet, we have outlined how and when we make decisions when your child is a baby, or if it is recommended that your child have cardiac catheterisation or surgery. We will also talk about consent, what this involves, and how we can support you in this.

Please talk to your consultant cardiologist and your cardiac nurse specialist if you would like to know more about treatment decisions and planning.

Finding out during pregnancy that my baby has a heart condition

Around 50 per cent of children with a congenital heart defect (CHD) that require treatment in the first year of life are diagnosed during pregnancy.

How will you diagnose and assess my baby?

If a heart condition is suspected or diagnosed during a routine or specially requested ultrasound scan, the unborn baby will be assessed by a fetal cardiologist and a fetal medicine consultant. The likely treatment needs will be discussed with you.

Other consultants may be involved with the assessment (including clinical genetics consultants), and there may be a recommendation for more detailed genetic tests to look at the baby's chromosomes.

What will happen next?

After full diagnosis, we will talk to you about the need for treatment and the treatment options for your baby. Termination of pregnancy may be an option; this will be discussed when diagnosis is at less than 24 weeks' gestation. If you choose to carry on with your pregnancy, we will talk to you about a plan to monitor your baby. We will decide together where to give birth, what delivery is safe for you, and what treatment will be needed after your baby is born.

What if my baby's heart condition is diagnosed after birth?

When a child's heart condition is diagnosed after birth, this will usually be by a paediatrician, or sometimes directly by a paediatric cardiologist. Most paediatricians will make an initial clinical assessment and then decide whether to refer to a specialist. Some paediatricians and neonatal consultants have special expertise in cardiology, and they are able to undertake the initial echocardiographic (ultrasound scan) assessment. They may assess your child first, and if your child has a significant heart condition, they will contact a paediatric cardiologist to confirm the diagnosis and to advise on the likely treatment needs.

What will happen when my baby is assessed by a paediatric cardiologist?

The paediatric cardiologist will undertake a full echocardiographic assessment of your baby and will discuss the findings, diagnosis and likely treatment plan. In complex conditions, more than one cardiologist may assess your child, and sometimes further tests such as CT or MRI scans or a cardiac catheter study may be required.

This is to give us all the information we need to be able to advise you on what we believe is the right treatment option. If there is a potential need for cardiac surgery, the information from the investigations will be reviewed at the joint cardiac conference. This is a multidisciplinary meeting of cardiologists, cardiac surgeons, cardiac anaesthetists, intensive care consultants and cardiac nurses. They will discuss the precise diagnosis and the options for treatment. A decision will be reached as to the treatment option that is going to offer the best long-term result for your child.

For many conditions, the treatment pathways are well established, and the decision-making is straightforward. However, each child is different, so different options may be discussed with you. The cardiac team will always be trying to find the best treatment option for each child, and they will welcome input from parents on what the family views as being the best option for them as a family. The team has a responsibility to offer the treatment that is in the best interests of your child, and they will take this responsibility very seriously.

My child is undergoing cardiac catheterisation

Many heart conditions can be treated by a ‘keyhole’ method of treatment called cardiac catheter intervention. Such treatments may be used to dilate narrow valves or arteries, or they may be used for the closure of certain heart defects such as atrial septal defect (ASD) and persistent arterial duct (PDA). The treatment options will be discussed with you, and the balance of risks of treatment for the different options will be explained. Some more complex conditions may be discussed at the joint cardiac conference, but the majority will not require this, as treatment strategies are well established. You will have the opportunity to discuss the treatment with one of the cardiologists that undertakes such procedures – either in the outpatient clinic or on the admission to hospital for treatment. If you would like to have more detailed discussion before admission, it is important to let the treating cardiologist know so that a suitable clinic appointment can be arranged.

My child is undergoing cardiac surgery

Many congenital heart conditions will need to be treated surgically. An experienced surgical team that specialises in the treatment of congenital heart defects will undertake this treatment. The treatment options for the treatment of your child will be discussed at the joint cardiac conference by a multidisciplinary team of paediatric cardiologists, cardiac surgeons, cardiac anaesthetists and intensive care specialists. You will have the opportunity to discuss the treatment options with your child’s cardiologist and the cardiac surgeon that is likely to be undertaking the surgery – either in the outpatient clinic, or on the admission to hospital for treatment. If you would like to have more detailed discussion before admission, it is important to let your child’s cardiologist know so a suitable clinic appointment can be arranged.

Should I be worried about the risks of catheter or surgical treatments?

It is always important to balance the risks of treatment against the risk of alternative treatments. As part of the consent process for either a catheter or surgery, your cardiologist or the cardiac surgeon will advise you on the potential benefits of treatment and will discuss potential risks and complications. They will discuss worrying events like death and brain damage or stroke, as these are rare but very serious potential complications of treatment. The cardiologist or surgeon will always attempt to keep these risks as low as possible, but they cannot be completely prevented, so it is important that you are aware of these risks. They will describe the known risks, but there are rare complications that cannot be prevented or predicted. It is always important to keep these risks in proportion, as there are risks if you do not undertake such treatments. Your cardiologist or surgeon will advise you on the treatment that is believed to offer the best chance of success with the lowest risk of serious complications; this advice will be based on their own experience and that of other treatment centres.

What is the National Congenital Heart Disease Audit (NCHDA)?

All specialist cardiac surgical centres submit anonymised information on all cardiac catheter and surgical procedures to the National Congenital Heart Disease Audit (NCHDA). As part of the consent form, there will be a request for your permission to send such data to the national audit. The purpose of the audit is to monitor the standards of treatment offered around the country, and to ensure that all centres offer high quality treatment. Your child's information will be kept confidential to the treating centre, but the overall outcome of treatment will contained within the publically available data presented on the NCHDA website public portal: **https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home**. If you wish to check on the outcomes for a particular procedure, information on the results of treatment in the different centres is available on the website.

Can I ask for a second opinion?

There are some occasions when it can be difficult to determine the best treatment for your child. In some rare cardiac conditions, there may be another centre that has more experience of this condition, and for some children, transplantation is an option that may need to be considered. In these circumstances it is common practice for the cardiac team to seek a second opinion on the management of your child. This will usually require them to send details of your child's clinical information and of any diagnostic imaging that is available, so that the second centre has all the relevant information to be able to offer their opinion. The second centre may need to examine your child and perhaps undertake some further investigations before discussing the treatment options.

It is also possible for parents to seek a second opinion if they are uncertain of the advice they have received. This can be requested by your GP, but it is best done via your primary cardiac team, as they will have the relevant information and investigation results that they can send to the second centre. It is probably best to discuss this with your primary cardiac team, as they will often know which centre is likely to be have the most experience with your child’s heart condition and therefore offer the most appropriate advice. Your primary cardiac team will not be offended by your request for a second opinion if you are undecided about the best option for your child.

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 your child is under our care, you may be approached about them taking 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.

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