



**University Hospitals  
Bristol and Weston**

NHS Foundation Trust

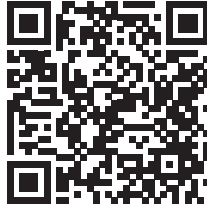
Patient information service  
**Bristol Royal Hospital for Children**

# Preparing for heart surgery



This leaflet gives you more information about what to expect if your child requires surgery for a heart condition. We hope that it will answer some of the questions you may have, but if you have any other queries, please talk to us. You will find a list of useful telephone numbers at the back of this leaflet.

**For a digital version of this leaflet please scan the QR code:**



When your child's consultant feels there is potential your child may require cardiac surgery, they will be discussed at a joint cardiac conference (known as the JCC) held weekly between the cardiologists, surgeons, anaesthetists, nurses and other specialist support staff.

During this meeting, your child's clinical condition and investigations are evaluated by the multi-disciplinary team (MDT), and a plan for their care is agreed.

Your cardiologist will write to you, explaining the options and the proposed plan, with the agreed outcome from this meeting and if a surgical intervention is required.

You will be invited to meet with a member of the surgical team in due course.



# What will happen at the surgical clinic?

The team will talk to you about a number of things, including:

- the type of operation
- why they feel it is important for your child to have this done
- the prognosis (likely outcome) if your child doesn't have the procedure
- the risks and benefits to your child
- the approximate timescale for surgery
- advice about good dental hygiene to protect your child from infection.

It is imperative your child is dentally fit prior to cardiac surgery. Therefore please ensure they have been seen and deemed dentally fit within the last 6 months by your local dental team. Please contact the CNS team if you are experiencing any difficulties getting a dental appointment.

This consultation is extremely important, as we try to make sure that you are as prepared for the forthcoming operation as you can be. You may want to have a notebook with you or have someone with you for this appointment.

We would encourage you to contact one of the cardiac nurse specialists if you have any questions after this appointment. Alternatively, you can ask the surgeon when you meet them again the night before surgery.

## **When will the operation happen?**

Each patient is reviewed according to their needs, and we will make a decision about how long is safe for your child to wait. Urgent or emergency patients will take priority.

Once a date has been decided, the cardiac coordinator will let you know and arrange for your child to be seen in the pre-admission clinic. It may take time to arrange a date, but if you are concerned about any delay, please contact the cardiac surgery coordinator on **0117 342 8221** and they will be able to check for you.

## **How much notice will we receive when offered a date for the operation?**

We try to give you as much notice as possible. If you think you will be available to come in on short notice (72 hours or less), please inform the cardiac coordinator, surgeon or cardiac nurse specialist, and you will be placed on a 'short notice' list to be called if we have any availability.

If you are on the short notice list, you may only have a few days between notification and your surgery date. This will give you limited time to prepare, so you may want to consider what you would need to have in place to be able to accept a date at short notice and to feel comfortable about the timings. You can talk to the team about coping strategies if you feel this would be helpful. Contact the clinical nurse specialists or psychologist for support and advice.

# Who is there to support us?

There is a wide team available to support you and your child during your preparation. You can talk to the cardiac nurse specialist and the clinical psychologist, who are regularly available on the ward. The play specialist will be able to help your child understand and cope with their time on the ward, as well as providing activities and entertainment.

You can find out more about these services from your child's nurse.

If you need more practical support, you can ask for a referral to our family support worker, or contact her directly via the LIAISE team on **0117 342 8065**. LIAISE provides a patient and family support service.



**Clinical nurse specialist team**

## **Who do I contact if my child becomes sick after they have a date for surgery?**

Please contact the cardiac nurse specialist team if your child becomes unwell, or if they are in contact with any children with an infectious disease, e.g. COVID-19, chickenpox, etc. Once they have the details of your child's symptoms, they will notify the appropriate member of the team to decide if this will affect the timing of your child's surgery.

## **What will happen in the pre-admission clinic?**

This pre-admission clinic appointment is to check that your child is fit for surgery. It is also your opportunity to tell us about any particular needs your child may have, ask any further questions, or talk about any worries. The clinic is currently held in the outpatients department at the children's hospital. This is often quite a long appointment, taking up to four hours; it will include a number of investigations such as an echocardiogram, chest X ray, ECG, blood tests and nasal swabs.

Our clinical nurse specialists and our play specialists will also talk to you about how they can support you and your child, for example by offering distraction during tests or investigations that take place during the clinic. You may have an opportunity to discuss anaesthesia with a consultant paediatric cardiac anaesthetist. A research nurse will also see you if your child is eligible to take part in any of the research studies running at the hospital.

## **Can we see the ward before we are admitted?**

It may be possible to arrange a visit to the ward as part of your pre-admission visit, but if not, you can find pictures and a virtual tour on the paediatric intensive care unit (PICU) and Dolphin Ward web pages or on our children's website for younger patients. Both can be accessed from the main University Hospitals Bristol and Weston website: <http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/>

After the surgical procedure, patients are admitted to PICU, and then transferred to the high dependency unit on Dolphin Ward. If you wish to visit PICU in advance, this may be possible once you have been admitted to Dolphin Ward, before your child's operation.

## What happens if my child's operation date is cancelled?

We take cancelling a patient's operation very seriously and try to avoid this wherever possible. Unfortunately, it may be necessary to cancel an operation for one or more of the following reasons:

- an emergency patient has been admitted and needs to take priority
- previous operations may have taken longer than expected
- there may not be sufficient staff to do the operation safely
- there may not have been a PICU bed available due to emergencies
- your child may be unwell.

If your child's operation is cancelled at short notice, a member of the team will talk to you and advise you of the plan for rescheduling the procedure according to your child's clinical need. Your child's cancellation will be reviewed to ensure that all factors are taken into account when rescheduling the operation according to your child's clinical condition. If the plan to reschedule surgery changes following that discussion, we will write to you to advise of the new arrangements.

Please be assured that we have systems in place to ensure that patients on the waiting list for surgery are monitored and brought in for surgery according to their clinical need.

## What happens if there is a delay?

If your child's surgery has been delayed, their needs will continue to be reviewed by the cardiology and surgical team. If you feel their condition is worsening, please contact your clinical nurse specialist (**0117 342 8286**), or ask your GP to review your child and write to their consultant cardiologist. During this period, we may also need to ask you to come back to the pre-admission clinic; this is to ensure we have up-to-date information so we can keep your child safe.



## What if my child has additional needs?

Please discuss any additional needs your child has with the team during the clinic appointment. If your child has a disability or complex needs, it may be helpful to complete the hospital passport if you have not already done so, which will help staff understand the whole of your child's care needs. If you are worried about us jointly managing your child's additional needs during their admission, please speak to your cardiac nurse specialist or contact the LIAISE team. You can download the passport from the following link:

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/patient-and-family-support-services/disability-support-team/hospital-passport/>

## Arriving at the hospital

### What will happen when we arrive?

You will be admitted to the ward the day before your child's operation. This allows us to check that your child is well enough to undergo surgery. You will also be asked to sign the formal consent form at this time. This documents:

- that you have had the opportunity to discuss the operation with a surgeon
- that you understand why we believe it should be done
- what exactly is going to be done
- details of any risks associated with the procedure
- that you agree for us to proceed with the operation.

## **This is an extremely important consultation.**

If you have any remaining questions, this is the time to discuss them so that we can ensure you are as ready as possible to proceed to surgery. While every effort will be made to ensure that the surgeon you meet will be the surgeon performing the operation, this is not always possible. However, the surgeon carrying out your child's operation will always be highly experienced.

If you have concerns about this, please raise it with the nurse looking after you so that you can speak to someone in advance.

## **Will I see my child's consultant whilst my child is in hospital?**

We have a large team of consultants looking after all the families in the South West and Wales. This allows us to be able to deliver routine care for your child as close to where you live as possible and make things more convenient to you. However, this may mean that your 'usual' cardiologist is not around the hospital in Bristol when your child has their operation, although they will remain part of the discussions around your child's care.

To make sure that there is continuity in one person who is looking after your child, we have an 'attending cardiology' system. This means that each week there is one consultant cardiologist who looks after all the cardiology patients in the hospital. Each Friday, the attending cardiologist changes, and the consultant from the previous week will hand over responsibility to the next consultant.

## **Will there be more tests?**

The anaesthetist, who will be looking after your child during the operation, will also come to meet you and your child. This is an opportunity for you to ask questions, to discuss the anaesthetic options available to your child, and talk about intensive care.

The nurse who admits you to the ward will go through your family information and take your child's temperature, heart rate, blood pressure and saturations. They will tell you when your child needs to

stop eating and drinking. If you have not attended the pre-admission clinic, the nurse will also take your child's height and weight and arrange for a blood test, echocardiogram and ECG.

## **What if my child's procedure is cancelled on the day?**

Unfortunately, sometimes it may be necessary to cancel an operation on the day it is planned. If you are already at the hospital, we will do everything we can to rearrange the surgery within a short time to avoid a wasted journey. However, this may not always be possible, but the team will endeavour to assist you with regards to recouping losses incurred.



# **The day of the operation**

## **How do I help my child get ready for surgery?**

On the day of your child's operation, please ensure that your child has been bathed or showered. If they are older and wear jewellery or nail polish, please also ensure that these are removed. Your ward nurse and the anaesthetist will talk to you about what times your child will need to stop eating and drinking. Your child may also be given a 'pre-med' to help them be calmer before surgery.

## **Can I go with my child to theatre?**

When theatre staff call, your child will be taken down to theatre by a nurse. It is usually possible for at least one parent to accompany them down to the anaesthetic room; this is something that you can discuss the day before with the anaesthetist. A porter will push your child on the trolley. You can usually stay with your child until they are asleep.

## **Who will be involved in my child's operation?**

Heart surgery is very complex and therefore many people are necessary in theatre to do it safely. As well as the consultant surgeon and anaesthetist, there will be junior doctors to assist. There will be a scrub nurse, who directly assists the surgeon with the procedure, and theatre staff, who help to run the operating theatre, as well as a perfusionist if your child's operation is performed on bypass.

## How long will surgery take?

Before the operation, we will give you an estimated time of how long the procedure will take, but sometimes parts of the operation can take longer than we expect. This does not necessarily mean that anything has gone wrong. As well as the actual time to do the procedure, there is also anaesthetic time while your child goes to sleep and is prepared for surgery with the necessary catheters and equipment that the anaesthetist will have explained to you. Once your child has arrived in PICU, time is needed while the machines are set up and your child is settled there.



We understand that this can be a very stressful time. If you are worried that all this is taking longer than anticipated, you can speak to the cardiac nurse specialist or a nurse on the intensive care unit.

## Where should I go during surgery?

Your child's nurse will take you back up to Dolphin Ward. Following their operation, your child will be a patient on PICU, and so they will no longer have a reserved bed on Dolphin Ward. There is a storage area for one bag on Dolphin Ward while they are in PICU, so ask your nurse to show you where this is if required.

You may choose to stay in the hospital during the operation, however families have told us that it can be helpful to go out. Whichever you choose, we will make sure that we have a means of contacting you so we can let you know as soon as your child comes out of surgery. You can then go to the PICU parents' room and we will come to see you as soon as we are free.

## **Will you be able to update me during the operation?**

We will not be able to do this while your child is in surgery. This is because everyone in the operating team is focusing on your child's operation and it is important that they aren't interrupted. However, if there are any events that we need to talk to you about while your child is in theatre, we will contact you.

## **What to expect after theatre**

### **Where will my child go after surgery?**

PICU staff will contact you once your child has been settled into the unit. Your child will be monitored by a nurse by a bedside nurse and doctors will also regularly review your child.

The CNS team will give you the opportunity to talk about the immediate post-operative care your child will receive on PICU as part of your pre-admission preparation.

# What equipment will my child need after surgery?



After surgery, your child may have some of the following equipment and items attached to them.

## **Ventilator**

Your child may have a tube down their nose or mouth to support their breathing (ventilation) after surgery. For this, they will need to be sedated with medication. During their recovery, the ventilator will gradually be reduced until they are able to breathe on their own without the machine. They will then be 'extubated' (the tube removed). We may give them additional oxygen after this, either using a face mask or prongs inserted into the nostrils. In infants we may use head box oxygen, which allows us to give warmed, humidified oxygen that will allow them to cough and keep their lungs clear more efficiently.

## **Nasogastric tube**

This is a fine tube that is passed through the nostril into the stomach. This allows us to give food and medication.

## **Intravenous access and 'arterial line'**

Your child will usually have a small plastic catheter placed in their neck, often referred to as a 'central line'. This is a very important item, as it allows us to measure the pressure within the heart and also to give medications securely into the circulation. These include drugs that will help control the blood pressure. Another small plastic catheter will be placed into a vein somewhere else, usually a hand or foot, which will allow us to give fluids and other medications as required.

There will be a small plastic catheter inserted into an artery, most often at the wrist or at the top of the leg. This is often referred to as an 'arterial line'. It is used to monitor the blood pressure, to take out blood samples to check on the functioning of the lungs, and it informs us how best to set up the ventilator.

## **Monitoring**

Your child will be connected by wires to a number of other monitors that give us continuous information on a number of other vital signs. These include oxygen saturation, heart rate and rhythm, respiratory rate, temperature and blood pressure. These are all shown on a large monitor above your child's bed.

## **Pacing wires**

Most children will have little wires coming through their skin after a heart operation. Normally, these wires are wound up and attached to the child's chest, but sometimes they may be attached to a pacing box. They can be used to control the heart's rhythm, and are sometimes necessary after a heart operation if the conduction system in the heart has been affected by the operation.

If the pacing wires are being used, this is usually temporary. A day or so after the operation, if they are not being used, they can be removed by gently pulling them out. This is often done under sedation, particularly for smaller children. It is not painful, but creates a tickling sensation as they come out.

## **Chest drains**

After cardiac surgery, each child will have one or two chest drains coming out of their chest. These are necessary to remove any fluids that build up after the operation. The drains will remain in place until the fluid has stopped being produced. This may be a number of days after the operation. When it is time for them to be removed, they are pulled out after the child has been given some sedation. A black stitch is used to close over the small incision that is left behind. This stitch will be removed seven to ten days after the drains have been removed, either in the hospital or by your practice nurse.



## **Urinary catheter**

Each child has a catheter placed to drain the bladder after a heart operation. The amount of urine that is produced is a very sensitive and useful indicator of how the heart is functioning after the operation, and of how your child is recovering. It is therefore very important to know exactly how much urine is being produced.

## **Transfer to the ward**

### **When will my child transfer to the ward?**

Once the clinical team is happy that your child is stable after the operation and no longer needs to be on the intensive care unit, they will be transferred to the ward. This may be on the day after the operation or a number of days later; it depends on your child's progress.

Initially your child may go to the high dependency unit (HDU) if they require high dependency care. This is a very good sign that your child is on the road to recovery, and that they are ready to move from one-to-one care to the specialist care of the HDU nurses, who each look after two patients.

This care will usually be provided on Dolphin Ward in the specialist HDU, but it may also be provided on PICU on some occasions if a ward bed is unavailable.

Some patients may be well enough to go immediately back to a normal bed on the ward.

We realise this will be a time of adjustment, so please talk to the cardiac nurse specialist and the nurses caring for your child if you have any questions or worries.

## What's the difference between the high dependency unit and the rest of Dolphin Ward?

The High Dependency Unit allows us to step your child down from PICU whilst still providing elevated care outside of the intensive care unit.

While on HDU, your child's care will be jointly managed by the cardiology team and the high dependency team. You will have the opportunity to meet both of these teams on the twice daily ward rounds and we would encourage you to be present so that you can ask any questions.

When your child is well enough they will be moved onto the main part of Dolphin Ward. This is a further sign that your child is recovering well. During this period, we will start talking to you about discharge from hospital.

You can find out more about Dolphin Ward and discharge advice in separate leaflets. Please ask your nurse for a copy.

<b>Useful contacts</b>	
<b>Paediatric intensivists</b>	
Unit contact number	<b>0117 342 8437</b>
PICU consultants secretary	<b>0117 342 8843</b>
<b>Cardiac nurse specialists</b>	
Bristol CNS team	<b>0117 342 8286</b>
Cardiff CNS team	<b>02920 745 184</b>
<b>Ward team</b>	
Dolphin Ward	<b>0117 342 8332</b>
Cardiac psychology team	<b>0117 342 8168</b>
<b>Other support services</b>	
UHBW Switchboard	<b>0117 923 0000</b>
LIAISE family support team	<b>0776 101 8065</b>

## Useful contacts

### Cardiac surgeons

Andrew Parry	Lead consultant congenital cardiac surgeon
Massimo Caputo	Consultant congenital cardiac surgeon
Serban Stoica	Consultant congenital cardiac surgeon
Shaffi Mussa	Consultant congenital cardiac surgeon

To contact the surgeons, please call **0117 342 8862**.

### Cardiologists

Andrew Tometzki	Consultant in paediatric cardiology and Congenital Cardiac Network lead <b>Secretary: 0117 342 8853</b>
Catherine Armstrong	Consultant paediatric cardiologist <b>Secretary: 0117 342 8855</b>
Graham Stuart	Consultant paediatric and adult congenital cardiologist <b>Secretary: 0117 342 8852</b>
Srinivas Narayan	Consultant paediatric cardiologist <b>Secretary: 0117 342 8856</b>
Patricia Caldas	Consultant paediatric congenital cardiologist <b>Secretary: 0117 342 8853</b>
Demetris Taliotis	Consultant paediatric and adult congenital cardiologist <b>Secretary: 0117 342 8855</b>
Georgia Spentzou	Consultant paediatric cardiologist <b>Secretary: 0117 342 8852</b>
Camilla Snook	Consultant paediatric cardiologist <b>Secretary: 0117 342 8853</b>

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.uhbw.nhs.uk](http://www.uhbw.nhs.uk)

Help us prevent the spread of infection in hospital. Please make sure your hands are clean. Wash and dry them thoroughly/use the gel provided. If you have been unwell in the last 48 hours please consider whether your visit is essential.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking contact **NHS Smokefree on 0300 123 1044.**

Drinkline is the national alcohol helpline. If you're worried about your own or someone else's drinking, you can call this free helpline in complete confidence. **Drinkline on 0300 123 1110.**

For access all patient leaflets and information please go to the following address:  
<http://foi.avon.nhs.uk/>

**Bristol switchboard: 0117 923 0000**  
**Weston switchboard: 01934 636 363**  
**[www.uhbw.nhs.uk](http://www.uhbw.nhs.uk)**



For an interpreter or signer please contact the telephone number on your appointment letter.



For this leaflet in large print or PDF format, please email [patientleaflets@uhbw.nhs.uk](mailto:patientleaflets@uhbw.nhs.uk).

