



University Hospitals Bristol
NHS Foundation Trust

Patient information service
Bristol Royal Hospital for Children

Preparing for heart surgery



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Bristol Royal Hospital
For Children

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.

When your child is diagnosed with a heart condition, their needs are 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 discussed by the multi-disciplinary team (MDT), and a plan for their care is developed.

Once the decision is made that your child will need surgery, your cardiologist will write to you, explaining the options and the proposed plan, with an appointment for your child to be seen by the surgeon in clinic.

The cardiac coordinator will also tell you that your child has been put on the waiting list.



What will happen at the surgical clinic?

The consultant cardiac surgeon, cardiac nurse specialist, dental registrar and sometimes a research nurse will meet with you to discuss the proposed operation and what to expect.

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.

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 bring a notebook with you along with any questions you have. You may also want to bring someone to this appointment to support you. If you wish to record the conversation to help you remember the details, please ask the consultant about this.

It often happens that further questions come to mind after the consultation. If this happens, you can phone one of the cardiac nurse specialists to ask them. 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 8862** 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. This may be arranging care for other children, asking additional family members to be available to support you, organising transport, or notifying your workplace. 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 'Martha Care' 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 chickenpox. 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.

When we receive a date for the operation, will my child need to be seen again before the operation?

When you are offered a date for your child's operation, you will also be offered a date for the pre-admission clinic.

What will happen in the pre-admission clinic?

This pre-admission clinic appointment is to check that your child is well enough 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 every Thursday 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, electrocardiograph, blood tests and nasal swabs.

You will have an opportunity to discuss anaesthesia with a consultant paediatric cardiac anaesthetist. 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. 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 on the paediatric intensive care unit (PICU) and ward 32 web pages or on our children's website for younger patients. Both can be accessed from the main University Hospitals Bristol website: www.uhbristol.nhs.uk. If you would like to arrange a more detailed tour of the hospital, please ask your cardiac nurse specialist or contact LIAISE on **0117 342 8065**. After the surgical procedure, patients typically have a period in the recovery area, followed by admission to PICU, and then transfer to the high dependency unit on ward 32. If you wish to visit PICU in advance, this may be possible once you have been admitted to ward 32, 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 from time to time, and this usually happens 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 have been enough staff to do the operation safely, either in PICU or in theatre
- 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 cardiac clinical team will talk to you and advise you of the plan for rescheduling the procedure according to your child's needs. Your child's cancellation will be reviewed at the next

weekly Joint Cardiac Conference 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 needs. If, whilst you are awaiting a new date for surgery, you should have any concerns about your child's health, please contact a member of the clinical nurse specialist team to discuss these. When a new date is available for your child, we will either call you to confirm or, if planned sufficiently ahead of schedule, we will write to you to advise you of the new date and time for admission.

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 I am worried about my child's cardiac condition while they are waiting?

You can contact the cardiac nurse specialists, the ward team, or your child's consultant with general concerns. If you have serious concerns about your child's condition, please either contact your GP or telephone 111 for advice.

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:

www.uhbristol.nhs.uk/media/2195239/myhospitalpassport-1_1_.pdf

Arriving at the hospital

What will happen when we arrive?

We hope that we will already have seen you in the pre-admission clinic before the day of your child's admission. We will also need to see you and your child before the operation. This allows us to check that your child is well enough to undergo surgery. You will also be asked to sign the formal operation 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
- that there are risks with doing the operation (we will give details of what these are)
- that you want 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 on this day we have a 'grand round' at which a large number of cardiologists review together the care of all the children and young people. During this meeting, the consultant from the previous week will hand over responsibility to the next consultant.

This means that your child's consultant will be part of the discussions around your child's care (unless they are away) but may not be the consultant you see on the ward round each day. However, all of the consultants are highly experienced and will provide a high level of care for your child during their admission.

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 pressures 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 electrocardiogram.

Can we visit the intensive care unit?

Your nurse will usually be able to arrange a visit to the paediatric intensive care unit (PICU). This is a very big and busy room where your child will stay for observation following their surgery. Visiting PICU before your child is admitted will help you familiarise yourselves with the environment. We will try our very best to offer this to you, but it may not be possible if the unit is closed to visitors, which is occasionally necessary.

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 we know in advance that a cancellation is likely to happen, we will try to contact you before you leave home. 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. If your child's operation is cancelled, we will talk to you about the reasons.

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 child will need to stop consuming food or milk six hours before surgery but will generally be able to continue with clear fluids until their pre-med or until they are called for theatre. 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 your child down to the anaesthetic room; this is something that you can discuss the day before with the anaesthetist. Your child may need a hospital trolley if a pre-med has been given. 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?

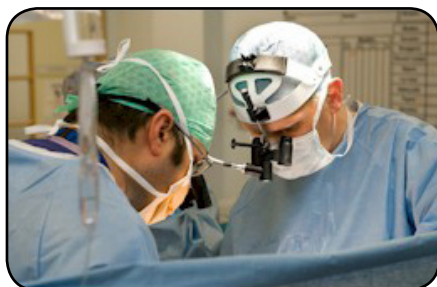
Heart surgery is very complex and therefore many people are necessary in theatre to do it safely. As well as the consultant surgeon and anaesthetist, there will be junior doctors to assist. There will be a scrub nurse, who directly assists the surgeon with the procedure, and some 'circulating' nurses,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

All these people will be doing their part in the 'operation'. On occasion and where appropriate, this may involve the junior doctors actually doing the major parts of the operation, though

they will always be supervised by the consultant who is in charge of the procedure. This will help train doctors so that they can help future patients in the hospital.

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 ward 32 to pack up your child's belongings. Following their operation, your child will be a patient on PICU, and so they will no longer have a reserved bed on ward 32. There is a storage area for your child's suitcase on ward 32 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, but 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?

Your child will be taken to PICU directly from theatre once the operation is complete. Here, your child will be looked after by a specialist intensive care nurse.

PICU staff will contact you once your child has been settled into the unit. Your child will be monitored by a nurse at the end of their bed, and doctors will also regularly review your child. The nurse will try to answer any questions you may have, and will refer to a doctor any questions they are unable to answer. The nurse looking after your child will give you a leaflet containing lots of useful information about what to expect while your child is in PICU.

It is important to realise that your child will look rather different immediately after surgery. They will look rather pale and may be puffy around the face and the eyes due to retained fluid. There will be breathing tubes attached by tapes to some parts of their face, and there will be dressings and catheters in various places, such as the side of the neck, hands and wrists, and in the groin area. The nurse looking after your child will explain what the tubes and lines are for.

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 five days after the drains have been removed, either in the hospital or by your district 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 ward 32 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 ward 32?

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. The ward rounds take place first thing in the morning just after breakfast time and again late afternoon, just before tea. Please speak to the HDU nurse looking after your child for specific times. Please remember that if you have any questions or concerns, you do not need to wait until the ward round to raise them; you can talk to your child's nurse, the nurse in charge or the ward sister, who will be able to help you.

If at any point during your stay you do not feel that your concerns or questions are being listened too we have information displayed within the ward that will advise you what to do.

After a time, your child will be well enough to move onto the main part of ward 32. The nurses here are all experienced in looking after patients following heart surgery or with heart conditions, and each nurse will look after three patients. 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 will find out more about looking after your child following cardiac surgery, and particularly what medications they need and what they do. Again, your child will be reviewed by one of the consultant cardiologists on the ward round every day, usually in the early part of the morning. This is an opportunity for you to meet the doctors and ask any questions you may have. We want you to be as much a part of the care of your child as possible, and we do not want you to worry about things when we can help reassure you. However, being able to contact your doctor is not solely limited to these times; if you ask your nurse, a time can be arranged for you to meet with anyone in the team.

You can find out more about ward 32 in a separate leaflet.
Please ask your nurse for a copy.

Useful telephone numbers

Cardiac surgeons

Andrew Parry	Lead consultant congenital cardiac surgeon
Massimo Caputo	Consultant congenital cardiac surgeon
Serban Stoica	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 Secretary: 0117 342 8853
Alison Hayes	Consultant in paediatric cardiology Secretary: 0117 342 8855
Robin Martin	Consultant paediatric and adult congenital cardiologist Secretary: 0117 342 8855
Graham Stuart	Consultant paediatric and adult congenital cardiologist Secretary: 0117 342 8852
Robert Tulloh	Clinical lead and consultant paediatric and adult congenital cardiologist Secretary: 0117 342 8856
Mark Walsh	Consultant in paediatric cardiology Secretary: 0117 342 8852
Patricia Caldos	Consultant paediatric and fetal congenital cardiologist Secretary: 0117 342 8853

Demetris Taliotis	Consultant paediatric and adult congenital cardiologist Secretary: 0117 342 8855
Michael Yeong	Locum consultant in cardiology Secretary: 0117 342 8854

Cardiac anaesthetists

Anaesthesia secretary	0117 342 7008
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Paediatric intensivists

Unit contact number	0117 342 8437
PICU consultants secretary	0117 342 8843

Cardiac nurse specialists

Contact number	0117 342 8286
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Ward team

Ward 32	0117 342 8332
Matron for critical care and cardiac services	0117 342 8754
Cardiac psychology team	0117 342 8168

Other support services

Bristol Royal Hospital for Children main reception	0117 342 8460
LIAISE family support team	0776 101 8065
Play team	0117 342 8194
Disability support	0117 342 8653

Notes

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.