

Your child's heart surgery

This leaflet gives more information about your child's heart surgery. If you have any questions or concerns, please speak to a doctor or nurse caring for your child.

Your child's cardiologist has decided that your child has a heart condition that needs surgery. You will meet the surgeon before the operation, and they will explain what the surgery is and why it's recommended, as well as any risks and possible complications. You will be able to ask the surgeon questions, but this leaflet will help you understand a bit more about heart surgery beforehand, and help you think about what you might want to ask the surgeon or anaesthetist.

When you know your child is having surgery

Depending on the age of your child, how far away you live and the nature of the surgery, you will probably come into the hospital about a week before the operation for a pre-assessment appointment. If your child is already in the hospital, they will have the tests as an inpatient. If you live very far away, your child might have their pre-assessment appointment the day before the surgery.

At the pre-assessment appointment, your child will be examined by a member of the cardiology team. They will have some blood tests, an echocardiogram, ECG (electrocardiogram), and a chest X-ray. This is usually when you meet the surgeon and have the opportunity to ask questions. The surgeon will ask you to sign a consent form to allow the operation to go ahead.

While we try to book operations in advance and stick to our plans, emergencies and other unexpected circumstances mean that we cannot guarantee that the operation will take place on the day or time booked.

Preparing for surgery

Fasting (not eating or drinking) instructions (also called 'nil by mouth')

The operation will take place under general anaesthetic (your child will be completely asleep) so it is important that you follow the instructions that you're given in the pre-assessment appointment about when your child must stop eating and drinking.

If there is food or liquid in your child's stomach while they are under anaesthetic, it could come up to the back of their throat and damage their lungs. If your child has any additional health conditions, such as diabetes or another metabolic condition, please ask the medical staff for more advice about fasting.

If the operation is delayed for any reason, your child's nurse will tell you if your child can be given a drink of water or other clear fluid to prevent excessive thirst and dehydration.

Some children who are at higher risk might need a cannula (thin plastic tube into the vein) so that they can have fluids while they are fasting.

Medicines

If your child is taking medicines, you should continue to give them as usual up to the day of admission, unless your cardiologist or surgeon tells you not to. If your child is on blood thinners (for example aspirin, clopidogrel, warfarin) you will be given a specific plan about when to stop. Some children might need to be admitted for heparin injections before the operation, but the cardiologist will update you with the plan.

Risks and possible complications

Risk to life (death)

All surgery, however minor, has associated risks of death and other complications. These risks are related to the anaesthetic and the surgery. For many operations the risk is very low, but there is never 'no risk'. Complications can happen either during surgery or soon afterwards. The risks are different for each case and depend on many factors including:

- the age, weight and prematurity of your child
- the nature of your child's heart defect
- How well your child is going into surgery
- additional medical conditions that your child may have
- previous cardiac surgery
- the type and complexity of the surgery

Heart surgery is only done when the:

- risk of operating is less than that of not operating
- when the potential benefits of the operation substantially outweigh the risk

Sometimes it is best to do surgery when the child is well, as delay could lead to a greater risk later on, or even make the operation impossible.

In most operations the risk of death is less than 1 patient in every 50 (below 2%) and often less than 1 in 100 patients (below 1%). Some rare and highly complex operations might have risks as high as 1 in 2 patients (50%).

In rare circumstances, the exact operation needed might only be decided when the surgeon looks inside the heart and can see what is safest and has the best outcome. Occasionally a more complex or less complex operation than expected might be done.

Risk of complications

Some complications are specific to the type of operation or to the cut (incision) used, for example, when operating through the side of the chest or using the heart-lung machine. Some of the complications that can occur include the following.

Bleeding

All surgery can cause bleeding, especially heart surgery, and a blood transfusion is often required, as well as other blood products that help the blood to clot. Sometimes the surgeon will have to re-open the wound to deal with bleeding.

Infections

Any cut can get infected, although most children heal up very well. Infections in the lung (pneumonia), urinary system, or blood stream (sepsis) are all possible, and are because of the complexity of the surgery and the duration of recovery.

Mycobacterium chimaera

This bacterium is a very rare cause of infection. It is thought to be related to an essential item of equipment (heater-cooler) used in open heart surgery. No cases have been reported in children, and most only after valve operations in adults. The estimated risk in adults is between 1 in 5,000 and 1 in 2,000. The infection can appear up to 5 years after surgery.

Fluid collections in the chest cavity (effusions)

These can build up during the recovery period and might need to be drained by inserting tubes into the chest. This can occur around the lungs (pleural effusion) or heart (pericardial effusion). The fluid may be watery, blood or fatty (lymphatic). Sometimes a special diet (low fat or fat-free) will be required if it is fatty fluid.

Heart failure

Sometimes the heart might be weak before or after the operation, and need medicines to boost its pumping action. Very rarely, an ECMO (extracorporeal membrane oxygenation) pump is needed to help the heart recover from the operation. If your child needs this, you will be given more information.

Kidney injury

This is quite common but does not usually last long. The kidney is very sensitive to any disturbance of the circulation. Most children need medicines to help the kidneys function for 4 to 6 weeks after surgery. Some need dialysis immediately after surgery, but once the heart has recovered, the kidney almost always recovers and functions normally again.

Brain damage

Severe brain damage is rare. Some children have abnormal movements or fits during the recovery period, which might be related to fever or a biochemical disturbance. Full recovery is the usual outcome. Even if obvious brain damage occurs, children tend to recover better than if the same damage occurs in an adult.

Gut

The intestine is sensitive in newborns, especially in premature babies or those with complex cardiac conditions, so feeding must be carefully managed. Sometimes the baby needs to be fed through a drip into a vein for a few days, to allow the intestine to rest and recover. Sometimes a serious gut infection called NEC (necrotizing enterocolitis) can develop. This can usually be managed with antibiotics and resting the gut, but sometimes needs gut surgery to remove the damaged region of gut or to rest the gut temporarily by bringing the intestine out to the skin to create a stoma.

Damage to other cardiac structures

Valve damage is rare. The heart's electrical system (conducting tissue) is close to where stitches sometimes need to be inserted. This means it can get bruised and not work, and a pacemaker might be needed. In most cases this is temporary until the bruising settles, but in a few cases it is permanent.

Nerve damage

The nerves controlling the diaphragm (breathing muscle) pass close to the heart and can get damaged, affecting the ability to breathe. This can result in difficulty weaning from the ventilator. The nerve that controls the left vocal cord in the voice box is close to the aorta (main artery from the heart) and can be damaged during some operations on the aorta or nearby structures. If this nerve is damaged it can lead to a hoarse voice. Both of these nerves usually recover.

All of these complications are rare, but can occur alone or with others, even when surgery has been successful. When severe, they can mean that your child needs to be in intensive care, or the hospital for longer than usual and need additional treatments or procedures.

These notes are not intended to be comprehensive and parents should feel free to ask any questions or seek clarification on any of the points raised.

Support and more information

Evelina Children's Heart Organisation (ECHO)

This is the parent support charity devoted to children and families who have had treatment for a heart condition at the Evelina London Children's Hospital.

<https://echo-uk.org>

Contact us

If you have any questions about your child's heart surgery, speak to the team looking after your child or the cardiac nurse specialists (CNS), **phone:** 020 7188 4546, **email:** PaediatricCardiologyCNS@gstt.nhs.uk

In an emergency, seek medical advice from your GP, 111 or go to your nearest emergency department (A&E).

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web:** www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline, **phone:** 020 7188 3003, Monday to Friday, 10am to 5pm **email** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone:** 020 7188 8801 **email:** pals@gstt.nhs.uk. To make a complaint contact the resolution department **phone:** 020 7188 3514 **email:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please contact the department your appointment is with.

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing, **web:** www.nhs.uk



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