

Your child's heart surgery

This leaflet provides information for parents of children undergoing heart surgery. If you have any further questions or concerns, please speak to a doctor or nurse caring for your child.

Your cardiologist has decided that your child has a heart condition that requires surgery. You will meet the surgeon before the operation who will explain the nature of the surgery and why it is recommended, as well as the principal risks and potential complications. You will have the opportunity to ask the surgeon questions, however this leaflet is designed to 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.

What happens next?

Depending on the age of your child, how far away you live and the nature of the operation, you may come into hospital on the morning of the operation, however most children come in the afternoon before or are already in hospital following the initial medical tests.

Children coming from home will be seen at a pre-assessment clinic about a week in advance where some blood tests, an ECG and chest X-rays are done. A paediatric doctor will see your child and check that they are well enough to have an operation. Often that is 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 first suggested.

Preparing for surgery

Fasting instructions ('nil by mouth')

The operation will take place under general anaesthetic (the child is completely asleep) therefore it is important that you follow the instructions that will be given in the pre-assessment clinic about when to stop eating and drinking.

It is important to follow these instructions, as 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 some other metabolic condition, please ask the medical staff for further advice about fasting.

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

Medicines

If your child is taking medicines, you should continue to give them as usual up to the day of admission, unless your cardiologist/surgeon tells you to stop.

Risks and possible complications of children's heart surgery

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. While in many operations the risk is very low, it is never zero. Heart surgery is no exception. Complications may occur either during surgery or in the early post-operative period soon after. The risks vary from case to case and depend on many factors including:

- Age, weight and prematurity of the child
- Nature of the heart defect
- Condition of the child
- Additional medical conditions
- Previous cardiac surgery
- Type and complexity of the operation.

Heart surgery, like all surgery, is only performed when the risk of operating is less than that of not operating, or when the potential benefits of the operation substantially outweigh and therefore justify the risk. In some children, in order to gain maximum benefit an operation may be performed when the child is well, as delay could result in greater risk later on or even make the operation impossible.

In the majority of operations the risk of death is below 2% (less than 1 in 50) and often below 1% (less than 1 in 100). However some rare and highly complex operations may have risks as high as 20-50%.

In rare circumstances, the exact operation needed may only be determined once the surgeon looks inside the heart and is able to finally decide what is safest and best for the future. Therefore, occasionally a more complex or a less complex operation than expected may be performed.

Risk of complications

Some complications may be specific to the type of operation or to the incision used, for instance when operating through the side of the chest or using the heart-lung machine. Complications that can occur include, but are not restricted to, the following:

- **Bleeding** - All surgery can cause bleeding, especially heart surgery, and it often requires blood transfusion and other blood products that assist clotting. Sometimes the surgeon will have to re-open the wound to deal with post-operative bleeding.
- **Infections** - Any cut can get infected, though most children heal up very well. Infections in the lung (pneumonia), urinary system or blood stream (sepsis) are all possible and relate to the complexity of the surgery and the duration of recovery.

- **Mycobacterium chimaera** - This bacterium is a very rare cause of infection but has emerged recently. It is thought to be related to an essential item of equipment used in open heart surgery, the heater-cooler. So far no cases have been reported in children and most only following valve operations in adults. The estimated risk in adults is between 1 in 5000 and 1 in 2000. The infection may appear up to five years after the operation. Further information is available at: www.nhs.uk/conditions/mycobacterium-chimaera-infection
- **Fluid collections** in the chest cavity (called 'effusions') can build up during the recovery period and may need to be drained off by inserting tubes into the chest.
- **Heart failure** - In some cases the heart may be weak at the outset or after the operation, and need special medications to boost its pumping action. Exceptionally, a specialised assist pump called 'ECMO' may be needed to help the heart recover from the operation.
- **Kidney failure** - This is not uncommon but usually of short duration. The kidney is very sensitive to any disturbance of the circulation. Most children need drugs to help the kidneys function for the first four to six weeks after the operation. Some may need extra treatment with dialysis in the immediate post-operative period, but once the heart recovers the kidney almost always recovers and functions normally again.
- **Brain damage** - Severe brain damage is not common thanks to modern equipment specially designed and manufactured for children's heart surgery, modern intensive care and anaesthesia, as well as a greater understanding of the nature of heart defects and how best to manage them. Some children may have abnormal movements or fits during the recovery period which may be related to fever or biochemical disturbance. Full recovery is the usual outcome. Even when obvious brain damage has occurred, children have a greater capacity for recovery than when the same damage occurs in an adult.
- **Gut** - The intestine is sensitive in the newborn, especially in premature babies, so feeding must be carefully managed. In some cases the baby may be fed through a drip into a vein for a few days to allow the intestine to rest and recover.
- **Damage to other cardiac structures** - Valve damage is rare. The heart's electrical system (called the 'conducting tissue') is close to where stitches sometimes need to be inserted, so it can get bruised and not work, meaning that a pacemaker may be needed. In most cases this is temporary until the bruising settles, but in a few cases may be 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 left vocal cord nerve is close to the aorta (main artery from the heart) and is in danger 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 can recover, though they may not always.

All these complications, while rare, can occur alone or in combination, even when surgery has been successful. When severe, they may cause delay in discharge from intensive care or hospital.

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

Useful sources of 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>

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.

t: 020 7188 3003 10am to 5pm, Monday to Friday **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** 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 get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership



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