



Oxford University Hospitals
NHS Foundation Trust

Children's Cardiac Surgery

**Information for
parents and carers**



The Children's Hospital

What are the benefits of having surgery?

Heart problems in children can be very simple or complex. For some children, an operation is the best way of helping improve their quality of life.

There are lots of different types of heart problems. The benefit of surgery will be different for each child.

- For some complex conditions, surgery will not correct the problem. This is sometimes referred to as palliative surgery and benefits the child by improving their quality of life.
- For children with an uncomplicated heart condition, surgery may be carried out to correct a defect and to improve the child's long term health and wellbeing.
- For children with serious heart conditions, the problem can be life-threatening. Surgery may be needed to save the child's life.

The medical staff will talk with you in detail about the type of surgery your child needs, including the benefits and risks.

Cardiac surgery is not carried out in Oxford. This will take place in another Children's Cardiac Surgical Centre.

What are the risks of having surgery?

All surgery has risks. These risks can come from:

- having an anaesthetic
- the actual surgery.

For most children these risks are quite low; however we cannot promise a risk-free operation. There is always a risk of death when complicated and major surgery is carried out.

Complications may happen during your child's operation or in the early recovery period after the operation.

The risks are different for each child and can depend on many things. These include:

- your child's age. Generally operations on newborn babies carry more risk than in older children
- your child's general condition
- other medical conditions, e.g. bowel or kidney problems
- the type of heart problem your child has
- the type of surgery and how complicated it is, including whether the surgery requires the use of the heart-lung (cardio-pulmonary bypass) machine
- any surgery your child has had previously.

The surgeon will explain to you in more detail what the risks are for your child for their surgery.

What are the risks during and after the surgery?

Complications are problems that can happen during or after your child's operation. Some complications may be specific to the type of surgery, for example if the operation is carried out from the side of the chest or if a heart bypass machine is used.

Complications can include:

- **Bleeding** around the area of surgery. Your child may need a blood transfusion or sometimes another operation.
- **Infections.** Wound infections, Blood stream infections, Chest infections or pneumonia
- **Fluid collecting** in the chest, around the heart or the lungs. If this happens, your child may need to have a small plastic tube (drain) inserted, to remove the fluid.
- **Chylothorax**, where lymph fluid leaks into the space between the chest wall and the lung. If this happens, your child will need to have a chest drain put in. Your child may also need to have a special low fat diet for several weeks.
- **Kidney failure.** This is usually rare, but more common in infants. Children usually recover well, although dialysis may be necessary.
- **Neurological** complications are rare and children tend to recover more quickly and better than adults. Rarely, there may be permanent damage. Convulsions (fits) occasionally occur after surgery; these are rarely a sign of brain damage and are most likely to be due to an electrolyte imbalance.
- **Heart rhythms.** The electrical system which controls the heart rhythm may be affected by surgery. This may require temporary pacing, or rarely a permanent pacemaker. Usually the heart rhythm returns to normal within a week or so.

- **Damage to nerves.** This may lead to problems with the diaphragm, which is a thin muscle below the lungs and heart that separates the chest from the abdomen. This may mean your child needs to be on the ventilator for longer and may need an operation on the diaphragm itself to correct the problem. The nerves that supply the vocal cords can also be damaged during surgery or by ventilation. Very rarely, a permanent hoarseness or rough-sounding voice can occur.

Although these complications are rare, your child may experience one or more of them, even when surgery has been successful. Sometimes these complications mean that your child may have a longer stay in the Intensive Care Unit or sometimes may need to go back there from the ward.

What is cardio-pulmonary bypass?

If the surgeon is operating on the heart itself, it needs to be empty of blood and stopped so that the surgeon can carry out the repair. This means that for a short time the heart-lung (cardio-pulmonary bypass) machine takes over. This machine will pump blood around the body and will take over the job of the lungs, adding oxygen to the blood and removing carbon-dioxide.

Due to the effects on the body of cardio-pulmonary bypass, children often become rather 'puffy' afterwards, particularly in the face, but their hands, feet and abdomen may also be swollen. This usually disappears within a few days of surgery.

Preparing your child for hospital

There are many different ways you can prepare your child for their hospital stay. Preparing them by giving them information can reduce fear and anxiety and increase their co-operation in procedures. Understanding a bit about what is happening to them helps children to cope better. Also, reducing anxiety has been shown to help speed up recovery.

How can I prepare my child?

Start by talking to your child, to understand how much they know about their visit to hospital. This will give you an idea of how much you need to tell them and the chance to correct any misunderstandings they may have.

When telling your child about their visit it is important to be truthful and give them detailed, factual information.

As young children have little concept of time, it may be best to prepare your child a day or two before admission. This can be done through a variety of methods, depending on the age of your child.

- **Stories.** There are many books available, which describe going for an operation; some are listed on the following pages. Ask your local library, bookshop or nursery/school if they have these books available. We have certain books available for you to borrow.

Anatomy and physiology books may be useful for explaining to older children.

- **Imaginative play.** This is a successful method of explaining things to young children (especially between the ages of 2 to 7). Hospital procedures, such as taking temperatures can be played out using dolls or teddies. Perhaps you could set up a teddy hospital and get your child to nurse them all better. Hospital play can also be acted out using play medical kits, toy hospitals and ambulances, dressing up outfits or puppets.

- **Play specialists.** Are available to help prepare your child for their operation once they are admitted, and have many specialised resources for this. There is a playroom on the ward where your child can be amused and occupied during their stay.
- **Post procedural play.** It is sometimes beneficial to talk about or play through a child's experiences of hospital after their operation. This can aid recovery and reduce any feelings of stress.

Book list

Miffy in hospital

Dick Brun. A simple story, suitable for toddlers.

Topsy and Tim go to hospital

Jean and Gareth Adamson. Tim bumps his head and visits the hospital. Whilst there he meets lots of different staff, goes for an X-ray and makes a lot of new friends.

Going to the hospital

Usbourne. Ben has an operation on his ear. This book tells the simple story of his operation and has lovely pictures.

I don't want to go to hospital

Tony Ross. The little princess decides she doesn't want to go to hospital, but once there doesn't want to go home. A fun book, which doesn't give too much information about hospital procedures.

Tomorrow I will feel better

Ann De Bode and Rien Broere. Rosie goes to hospital for a heart operation. Simple story with pictures, for younger children.

Talking it through – Going to the hospital

Althea. A great guide to hospital from a young person's point of view.

Zip Line

David Humpherys. For children who have a scar on their chest from heart surgery.

Riley's Heart Machine

Lori M Jones. For children with pacemakers.

Jessica has a heart operation

Louise George. Found on Little Hearts Matter website:
www.lhm.org.uk

Jack has a heart operation

Louise George. Found on Little Hearts Matter website:
www.lhm.org.uk

Books for older children:

Sammy's Heart Operation

A book for 7 to 11 year olds who are having heart surgery.

My Heart Op

A book for 13 to 19 year old heart patients who are having heart surgery.

Both from the British Heart Foundation

Website: www.bhf.org.uk

Having a heart operation

Pre-operative assessment visit

Your child will usually need to visit the Children's Cardiac Ward for some tests before their surgery. This is an ideal time to have a look around the ward, meet some of the staff and familiarise yourself with the hospital surroundings.

Tests they may have on the day include:

- blood tests
- ECG (electrocardiogram)
- chest X-ray
- urine test
- MRSA screening (nose swabs)
- echocardiogram.

Your child will also have a pre-operative examination by a doctor or Advanced Nurse Practitioner.

You will also have the opportunity to talk with one of the Children's Cardiac Nurse Specialists.

Admission for the operation

Children are usually admitted the day before their surgery. Nursing staff will help you and your child settle into the ward. Some paperwork will need to be completed about your child's general health, routines, etc. Your child will also need to have their temperature, heart rate, blood pressure and respiratory (breathing) rate checked and their weight and height recorded.

Before the operation, a doctor will come and explain the procedure again and will check that your child is well enough for surgery. Reasons not to go ahead would include diarrhoea and/or vomiting and a high temperature.

The anaesthetist will come and ask you some questions about your child's health. The anaesthetist is the doctor who will be sending your child off to sleep for their operation.

Consent

You will meet the surgeon at the pre-operative assessment visit, when you will be asked to sign the consent form.

The surgeon will explain the surgery, as well as any risks or complications. This is a good time to ask any questions you or your child may have.

Operation day

During the operation your child will be having a general anaesthetic. Your child will not be allowed to eat or drink for a while before the operation. This includes having chewing gum or boiled sweets. **It is important that these instructions are followed, for their safety.** If they have anything in their stomach whilst they are under the general anaesthetic, it might come back up and get into their lungs.

If these instructions are not followed, this may result in your child's operation being cancelled. We will tell you the precise time when your child is allowed their last food and drink.

Your child may have a 'pre-medication' (pre-med), which is a sedative. This is usually given 1 to 2 hours before the operation.

Your child will have 'magic cream' put on the back of their hands, to numb the skin before the cannula (drip) is inserted in the anaesthetic room.

When your child is ready to go to theatre, your child's nurse and both parents or carers can go with them. Usually only one parent or carer may go into the anaesthetic room.

Whilst your child is having their operation, we recommend that you go out, have a walk and something to eat and drink. If you prefer, you can wait on the ward.

When your child is out of theatre, and has gone to the Paediatric Intensive Care Unit (PICU), the staff will ring the ward and let you know when you can go and see them. You may be asked to wait a short time while they settle your child into the unit.

You can visit your child on the Paediatric Intensive Care Unit whenever you wish. It is requested that only 2 visitors are at the bedside at one time, as there is limited space. Brothers/sisters may visit if you feel it is appropriate; please ask for advice if you are unsure.

Recovering from surgery

When your child is ready to leave PICU they will continue their recovery on the ward.

Before you are able to take your child home we need to be sure that:

- they are eating and drinking a reasonable amount
- they are comfortable on oral pain relief
- they are mobilising (e.g. walking or crawling), appropriately for your child
- their wound is healing
- they have no fever or effusions (fluid collection)
- any post-op problems are improving, if they have any.

Leaving hospital

When you take your child home from hospital you may see a change in their behaviour. A stay in hospital can be stressful for a child, especially if they were admitted as an emergency. We hope this information will help you when you go home.

Changes in behaviour can include:

- bed wetting
- thumb sucking
- using a dummy or bottle
- fearfulness
- upset/tearful outbursts
- difficulties at school
- sleeping difficulties, e.g. nightmares
- aggression
- irritability
- demanding attention
- shyness/timidness
- feelings of rejection
- being clingy.

Reasons for possible changes in behaviour

Spending time in hospital can be difficult for children, for many reasons. Your child may be unable to tell you what is upsetting them and may express their fears through a change in behaviour.

If they feel insecure they may revert to babyish behaviour. They may not want to let you out of their sight, because they are worried you will leave them, no matter how many times you try to reassure them. Your child may also seem angry with you or reject you, because they feel frightened or threatened, or blame you for having to come into hospital.

What you can do for your child

Patience. After being in hospital, your child may need a lot of extra attention, love and patience. It may be difficult not to feel frustrated when they seem angry or aggressive with you. This kind of reaction is likely to be due to being in hospital and not from anything you have done. This can be particularly difficult at a time when you may already feel emotionally and physically exhausted, but try to remain as patient as you can.

Listening. It is important to listen to your child and show that you understand how they feel, for example "Yes, I know it felt funny. You didn't like it much."

Talking. Keep the subject of hospital in the family conversations. This gives your child the chance to talk about what happened. By talking about this with them you will be able to fill in any gaps, explain why things happened and correct any misunderstandings.

Playing. If your child shows signs of anger or aggression, try to divert this into play, e.g. hammering, active play, and outdoor and messy play, such as water play or playdough.

It may also be helpful to play 'hospitals', as this can help your child to act out their feelings and frustrations. Doing this can help them to understand and accept what happened to them. This kind of play may prevent problems if they need to stay in hospital in the future, as it gives them the chance to deal with any issues when they're fresh in their mind.

There are various toy medical kits on the market, or you can make your own. There are also many books, puzzles, games and toys with a hospital theme; these may be available from toy and book libraries.

It is important to remember that not every child will show a reaction to hospital, but if they do these changes in behaviour are normal and will usually get better within 6 weeks.

**For information about toy libraries and play services,
please phone the Oxfordshire Play Association:**

Telephone: 07436 270 267

Going home after heart surgery

Caring for the scar

By the time your child goes home their wound should need little or no care. Keep the wound dry and uncovered, if possible. Your child can continue to have shallow baths whilst the wound is healing, but must not get it wet. Normal baths and showers can be taken when the wound is completely healed.

Do not use creams (e.g. moisturising creams, vitamin E or medicated creams). These should not be applied to the wound area until it has completely healed (approximately 4 to 6 weeks).

If the wound becomes red, swollen or leaks fluid you should seek advice promptly from the Cardiac Nurse Specialists or your child's GP, as these may be signs of an infection.

Most of the stitches used during cardiac surgery are dissolvable and any visible ends will usually drop off. Please contact the Cardiac Nurse Specialists for advice if you have any concerns. Stitches that were holding drains in place may need to be removed after your child has left hospital. This can usually be arranged by the Practice Nurse at your GP's surgery or your Community Nurse.

It is also important to remember that scar tissue is more prone to sunburn. Keep the wound covered until it is fully healed and then use a high factor sun block to protect it.

Pain relief

For the first few days after going home your child may need an occasional or sometimes more regular dose of paracetamol. Do not exceed the recommended dose for your child's age. If their pain continues for longer than a few days or becomes more severe, please contact the Cardiac Nurse Specialists for advice. Your child can have pain relief at the same time as the cardiac medicines.

Signs and symptoms to look out for

In the first month or so after heart surgery, if your child develops a fever, aches and pains (flu-like symptoms), tummy pain, vomiting, a cough or breathlessness it is important to seek advice promptly from the Cardiac Nurse Specialists or your child's GP. These symptoms may be related to the surgery and need careful investigation and possibly treatment.

Please also look out for the following symptoms:

Babies

- increasing breathlessness
- increasing blueness
- poor feeding/sweating when feeding
- poor weight gain
- increasing lethargy or irritability
- puffy face or dry nappies
- unexplained high temperature.

Older children

- increased tiredness with physical activity
- lethargy
- poor weight gain
- unexplained high temperature.

Resuming normal activities

With toddlers and older children try to encourage quiet activities and avoid rough play for the first couple of weeks at home.

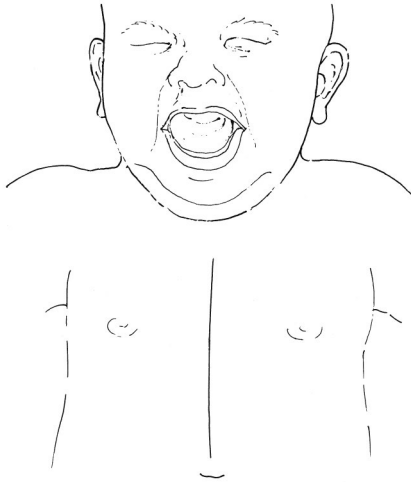
Your child should not take part in PE for 2 to 3 months after the operation.

Lifting and handling your child

Your child's wound will either be from a sternotomy or a thoracotomy.

Sternotomy wound

(a scar down the front of the chest)



If your child's scar is down the middle of their chest (a sternal wound), their sternum will have been divided and then wired back together at the end of the operation. This bone will take about three months to heal completely.

Thoracotomy wound

(a scar under the arm)



If your child has had a thoracotomy, their wound will be under their arm.

It is important that for the first few weeks you are careful about lifting them. You should be guided by your child's comfort and activity.

Lifting your baby this way may hurt



To begin with it might be painful for your child to be lifted in the usual way, under their arms.

This is the most comfortable way for your baby to be lifted



Following cardiac surgery your child should be able to travel home comfortably in a car seat/with a seatbelt. If they are uncomfortable, a small towel/blanket may be useful as extra padding, to prevent friction from the seatbelt (particularly for older children using the diagonal seatbelts).

For for the first 3 months your child should not take part in the following activities:

- contact sports
- climbing trees, climbing frames, trampolines, etc.
- cycling, horse riding.

Swimming should not be re-started until the wound is completely healed. Diving should be avoided for 2 months.

Your child should be encouraged to go out, but should avoid large crowds and keep away from anyone who is obviously unwell for a week or two.

Returning to school or nursery

About 6 weeks after going home your child should be ready to return to school or nursery. If they are tiring easily it might be necessary for them to go back part-time at first. It is important to make sure that any restrictions are understood by the nursery/school and by your child (if appropriate). If your child is keen to return to school earlier, please wait until their follow-up appointment and discuss this with the cardiologist.

Immunisation

Most children with a heart condition should be vaccinated according to the normal schedule. However, we would recommend that the immunisation programme should not be resumed until 4 weeks after surgery. Your child should also not be immunised within at least 2 weeks before their heart surgery.

Some children may have additional problems that affect their immune system, specifically children with DiGeorge Syndrome (22q11 deletion). Your child's cardiologist and immunologist will give you advice about how to proceed with the immunisation programme.

If your child is on warfarin or steroids, please ask their cardiologist or GP for specific advice.

Feeding your child

Babies with heart problems are often slower to gain weight. They often become breathless when feeding and tire more quickly. After your baby has had heart surgery, their weight gain and feeding should improve, depending on their underlying condition and treatment.

Sometimes it takes a while after surgery for children to return to their normal eating and drinking patterns.

Your child's GP and local paediatrician (if from a different hospital), will be informed of your child's treatment, any medication your child is taking or any special advice that is needed.

Going home

This can sometimes cause anxiety, particularly if you have not yet taken your baby home. There are people available to continue providing support. Your health visitor/midwife, Cardiac Nurse Specialist and children's Community Nurse are available for advice or any queries you may have. Please do ask.

It may take a little while for young children to settle back into their routines – we are very good at disrupting them in hospital! If you are concerned, please ask for advice.

It may be helpful to complete this checklist, to make sure you have all the information you need before going home:

- Understanding of diagnosis, surgery and long-term plans
- Signs and symptoms to be aware of
- Care of wound/removal of stitches
- Pain relief – what, how much and how often?
- Infective endocarditis prophylaxis/dental care
- Medicines – what they are for, how to give them and re-ordering
- Is any special equipment or feed needed to take home?
- Immunisations
- What your child can and cannot do
- Returning to school/nursery
- Who has been contacted about discharge, health visitor, Community team?
- Who to contact if concerned/have any questions
- Outpatient appointment – where and when

Useful phone numbers

If you have any questions or concerns, please contact us:

Children's Cardiac Nurse Specialists (Oxford)

Telephone: 01865 234 985

Oxford University Hospitals' Switchboard

Telephone: 0300 304 7777 – ask for bleep 4170

Email: childrenscardiacnursespecialists@ouh.nhs.uk

Children's Cardiac Nurse Specialists (Southampton)

Telephone: 02381 204 659

Southampton Cardiac Surgical Co-ordinator

If you have any questions about your child's surgical date please contact the surgical co-ordinator.

Telephone: 02381 205 382

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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