



# Children with Heart Conditions

A BOOKLET FOR PARENTS OF CHILDREN WITH HEART CONDITIONS



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## **How does the normal heart work?**

The normal heart is composed of four chambers. The two upper chambers (called atriums or atria) are reservoirs which collect blood as it flows back to the heart. From the atriums, blood flows into the lower two chambers (called ventricles) which pump blood, with each heart beat, into the main arteries. From the right side of the heart one of these arteries (the pulmonary artery) carries blood to the lungs for re-oxygenation. The left side of the heart pumps blood into the other main artery (the aorta), which takes blood to the rest of the body.

The two ventricles and the two atriums are separated by partitions called 'septums'. The partition between the atriums is called the 'atrial septum' and the one separating the two ventricles is the 'ventricular septum'. Dark red deoxygenated blood (shown blue in diagram) returns to the right atrium from the body through the two main veins called the 'superior vena cava' and 'inferior vena cava'. It is pumped by the right ventricle to the lungs for replenishment with oxygen. The dark blood becomes bright red (shown red in diagram) in the lungs when oxygen is taken up. This red blood returns through two veins from each lung, to the left atrium and is pumped by the left ventricle to the body again.

The heart has its own internal pacemaker which controls its rhythmical beating. It creates an electrical impulse which causes firstly the atriums, and secondly the ventricles, to contract in turn. With each contraction the blood is pumped, then the heart muscle relaxes and the chambers refill with blood, ready for the next contraction.

## **What are the heart valves?**

There are four valves which control the blood flow through the heart. They all consist of two or three flaps which swing open to allow blood through with each heart beat, and swing closed to prevent blood going back in the wrong direction.

Deoxygenated (blue) blood returning from the body collects in the right atrium. It flows to the right ventricle through the 'tricuspid valve'. It is then pumped through the 'pulmonary valve' into the pulmonary artery on its way to the lungs. Oxygenated (red) blood returning from the lungs collects in the left atrium and flows through the 'mitral valve' into the left ventricle. It is then pumped through the 'aortic valve' into the aorta and to the body.

## The Normal Heart

### Structures of the Heart

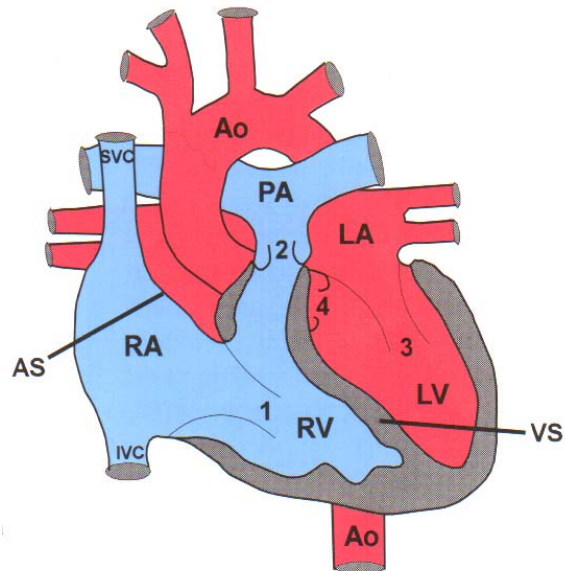
- LV - Left Ventricle
- RV - Right Ventricle
- LA - Left Atrium
- RA - Right Atrium
- AS - Atrial Septum
- VS - Ventricular Septum

### Valves

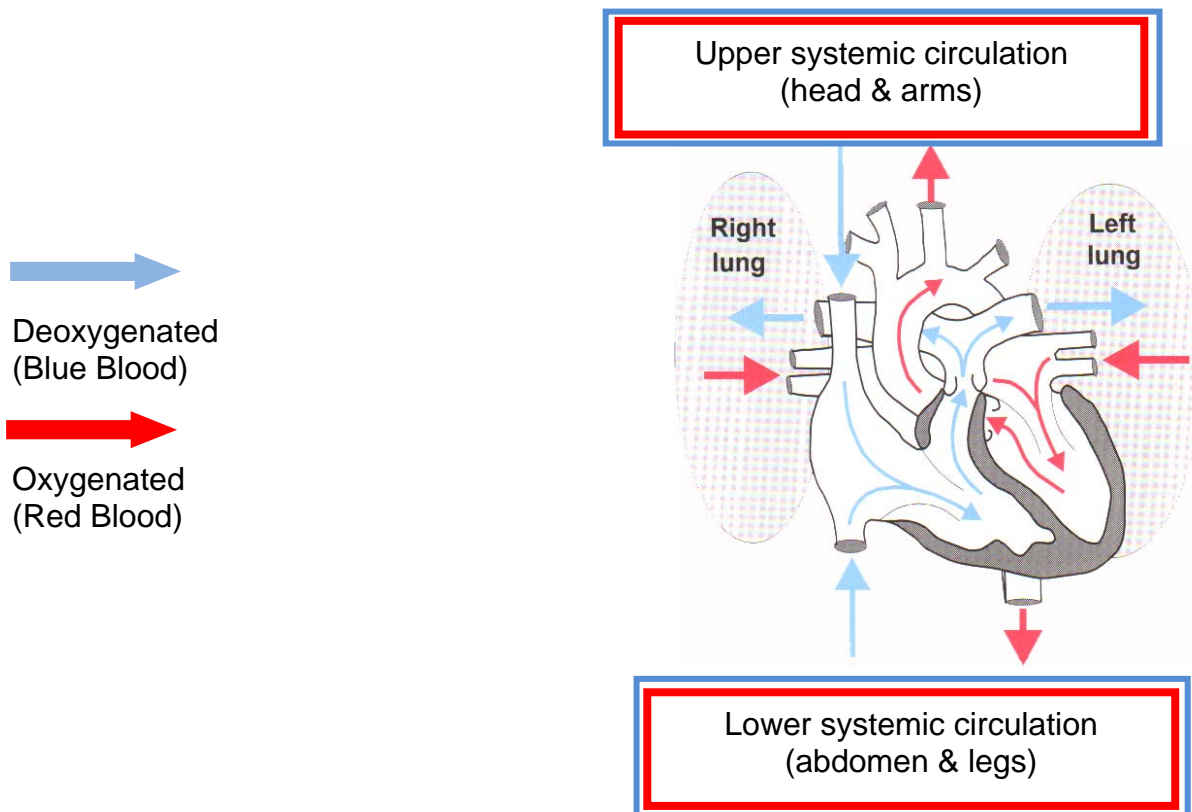
- 1 - Tricuspid Valve
- 2 - Pulmonary Valve
- 3 - Mitral Valve
- 4 - Aortic Valve

### Blood Vessels

- Ao - Aorta
- PA - Pulmonary Artery
- SVC - Superior Vena Cava
- IVC - Inferior Vena Cava

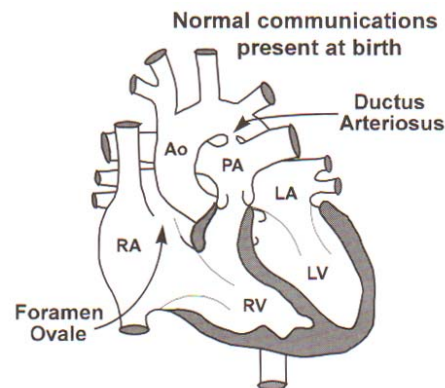


## Normal Circulation



## Are there any 'holes' in the normal heart when a baby is born?

Holes (or communications) between the atriums and between the two main arteries (aorta and pulmonary artery) do exist up until birth. These usually close in the early days or weeks after birth. These communications allow blood to bypass the lung circulation before birth, as the lungs are not yet functioning. The hole which connects the two main arteries outside the heart is known as the 'ductus arteriosus', while the hole which connects the two atriums is called the 'foramen ovale'. There is no hole in the partition between the ventricles in the normal heart when babies are born. Such openings are present in pregnancy during the early period of normal heart development, but they close long before birth.

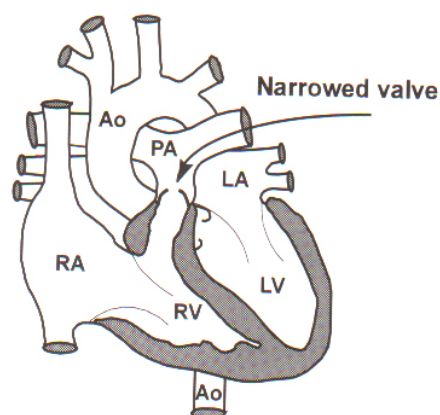


## What is meant by the term 'congenital heart disease'?

The phrase 'congenital heart disease' refers to the various abnormalities of the heart which are present at birth. Other words, such as disorder, defect, condition, or problem, may be used instead of disease.

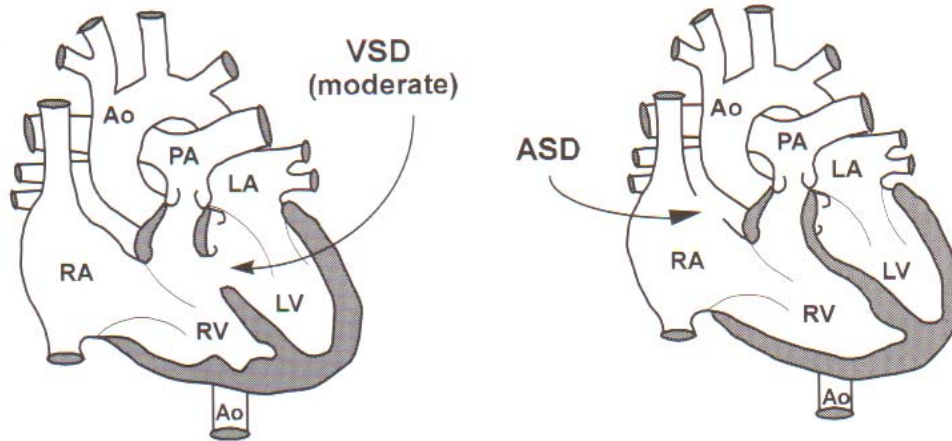
There are three main types of abnormalities:

1. There may be a narrowing (called 'stenosis') in parts of the heart, in its valves, or in the blood vessels outside the heart. This narrowing obstructs the flow of blood and puts strain on the heart muscle. In severe cases, the flow of blood past the obstruction may be reduced.



**Example:** Pulmonary Stenosis (narrowing of the pulmonary valve).

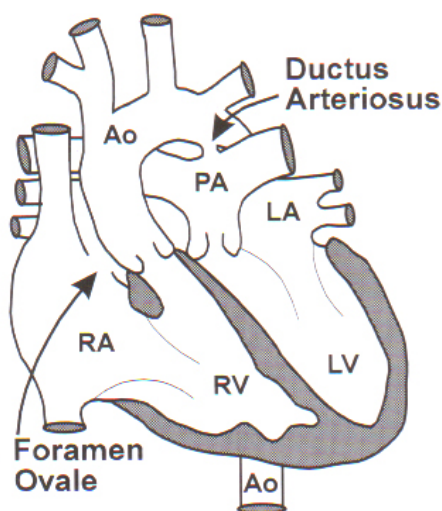
2. There may be holes in the partitions (septums) between the chambers of the heart. These allow blood to flow from one side of the heart to the other (called 'shunting'). As the blood pressure is higher in the left side, blood flows (shunts) from left to right and results in increased flow to the lungs. The normal communications present at birth may persist between the main blood vessels attached to the heart, e.g. Patent Ductus Arteriosus. This also results in increased blood flow to the lungs.



**Examples:** VSD (Ventricular Septal Defect) and ASD (Atrial Septal Defect).

3. The main vessels may be attached to the heart at an abnormal location.

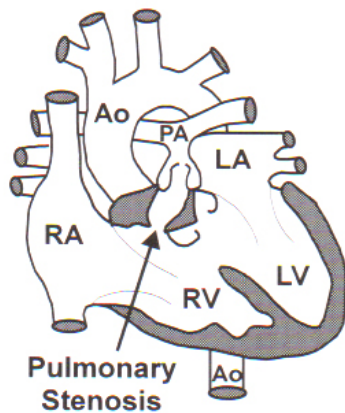
Example: Transposition of the Great Arteries.



In this abnormality, the aorta arises from the right ventricle and the pulmonary artery from the left ventricle. Thus the dark blood returning from the veins is pumped back into the main circulation, resulting in 'cyanosis' (blueness of the skin). In the newborn period, the ductus arteriosus and the foramen ovale are still open and allow some bright blood to get into the circulation. The baby will then usually survive for a few days at least, until effective treatment and surgery can be arranged.

Note: In some cases a combination of abnormalities may exist.

**Example:** Combination of VSD with Pulmonary Stenosis in Tetralogy of Fallot.



In this heart abnormality the way into the lungs from the right ventricle is narrowed (Pulmonary Stenosis). Some of the dark blood passes through the VSD into the aorta, resulting in cyanosis (blueness of the skin). Some affected babies may appear normal for several weeks or months before the blueness begins to develop as the narrowing becomes more severe.

### **How common are congenital heart problems?**

Abnormalities of the heart are present in nearly 1 in every 100 babies born. Some of these are mild and cause no significant disturbance to heart function. In many cases, such minor problems need no treatment and do not affect the life or the health of the child. More serious abnormalities are present in about five of these ten individuals with congenital heart problems.

The total frequency of all birth defects affecting different parts of the body is quite high. Some abnormality occurs in about 2.5% of all babies born. This, however, includes many minor abnormalities.

### **Why do congenital heart problems occur?**

In most cases the cause of the heart abnormality is unknown. By the end of the 7th week of pregnancy the heart is fully formed. It changes little in its basic structure until birth when the circulation of the blood alters as the lungs start to function. Major abnormalities in development of the heart must therefore occur early in pregnancy.

Parents will naturally worry about things which might have affected the formation of their child's heart. In most cases the heart abnormality is only an unfortunate occurrence which has not resulted from any identifiable cause. It has been identified that in approximately 20% of cases there are genetic errors which are responsible for the problem. If this is at all likely you may be offered a consultation with a geneticist.

Some illnesses in a pregnant mother may result in abnormalities in her baby's heart and vessels. One example is German measles (rubella), if contracted early in the pregnancy. Occasionally medications or alcohol taken during the pregnancy can cause problems - though small quantities of alcohol are not likely to cause harm. Many medications, which are needed during pregnancy for a wide variety of reasons and are prescribed by a doctor, do not lead to any damage to the baby. Smoking is certainly very undesirable during pregnancy, as it has adverse effects on growth of the baby and is associated with an increased rate of premature birth and stillbirth. However, there is no evidence linking smoking with heart problems in babies.

### **Will subsequent children have heart problems?**

In most families, abnormalities of the heart do not occur in siblings. In a few families, however, subsequent children may be affected. While it is inevitable that parents will be anxious about the health of their next baby, the risks are usually low. When one child has a congenital heart problem, the risk for the next pregnancy is usually between 2% and 4% (i.e. 2 in 100 to 4 in 100). It is often possible to diagnose a major heart abnormality on an ultrasound scan carried out at around four months or later in the pregnancy. Mothers who have had a previous child with a heart problem will naturally hope that any new baby will be healthy. If they wish to have a scan in subsequent pregnancies, they will need to be referred to one of the experts in this specialised field. Such scans will usually be carried out at one of the major obstetric units.

### **Can a child acquire a heart problem?**

While most children with a heart problem are born with it (congenital), there are some problems which may develop later (acquired).

Acquired heart problems include myocarditis (where the heart muscle becomes inflamed and may be damaged by a viral infection), cardiomyopathy (a disease of the heart muscle which can be caused by a genetic disorder or can develop following an infection), rheumatic heart disease (resulting from rheumatic fever which may lead to damage to the heart muscle and in particular to the heart valves), and Kawasaki disease (an illness that occurs in young children that may leave the heart muscle or coronary arteries damaged).

### **Will I need to restrict my child's activities?**

There is seldom any need to restrict the activities of children with a heart condition. Those who are cyanosed will usually restrict themselves as much as is needed. Those children who have no symptoms are not likely to come to any harm from participating in normal physical activities. Some parents are afraid that their child could die suddenly. Such events certainly can happen in adults with various types of heart disease, but fortunately they are very uncommon in children. If your cardiologist feels that any restrictions need to be made he will discuss this with you. Otherwise no limitations should be imposed. If you receive conflicting advice from different people on this matter (sometimes school teachers or local doctors may advise excessive restrictions), please ask your cardiologist to provide written instructions.

Parents often feel especially protective towards a child with a heart problem. It is important



that they treat such children as normally as possible and avoid being over-protective. Heart kids should be encouraged to become independent, to do things for themselves and take responsibility, as should normal children. Consistency in parenting a child with a heart problem is just as important as with other children.

## **Is a child with a heart condition at increased risk from infection?**

Your cardiologist will advise you about the importance of this for your child and will also be happy to give advice to your dentist or surgeon, on the appropriate management.

Most children with heart problems, who are otherwise well and free of any symptoms, do not need special antibiotic treatment for minor illnesses such as coughs and colds. They should usually be treated in the same way as other children who do not have heart problems. Only if they are needing medication for, or are symptomatic of, heart failure, do they need special attention for minor infections. In such cases, children should be seen by a doctor whenever they become ill so that, if necessary, treatment can be started early.

If buying medications over the counter, please check with your pharmacist, family doctor or cardiologist that the products will not complicate your child's heart condition or react with medication your child may already be taking.

The usual immunisations should be carried out at the normal time. If your child is unwell or receiving medications, you should check with your doctor or cardiologist to make sure that the immunisation will be effective and is safe to give.

## **How is a heart condition diagnosed?**

About one third of affected babies develop symptoms in the early weeks of life. The abnormalities which are present in some babies lead to mixing of dark (blue) blood from the veins with the bright (red) blood from the lungs. The blood then flowing to the body and its organs is dark instead of being bright. This produces a bluish colour of the lips and skin (called cyanosis), hence the term 'blue baby'.

In other children, even if blueness is not present, the heart may not be able to perform the extra work caused by the abnormality. Such children may develop symptoms, such as marked shortness of breath and difficulty with feeding. This is usually due to build up of fluid (congestion) in the lungs or other organs such as the liver. Doctors refer to this congestion as 'heart failure'.

In at least half of the children with heart abnormalities, there are no symptoms and the disorder is recognised when the child has an illness, or during a routine examination. The condition is usually recognised by the presence of a heart murmur, heard with the doctor's stethoscope while examining the heart. These murmurs result from turbulence in the flow of blood as the heart beats. Many heart abnormalities lead to greatly increased turbulence and hence produce quite loud murmurs. However, murmurs are not always due to heart defects and may have no significance. About 50% of children with normal hearts have faint heart murmurs. These 'innocent murmurs' tend to be more apparent during illnesses associated with fever, and this is when they are often detected.

If a heart defect is present, the nature of the problem and its severity must be assessed, and this will involve some tests. These are called non-invasive as nothing is introduced into the body during these tests. A recording of the electrical activity of the heart (ECG) are

usually required. The most important test is an ultrasound scan of the heart (echocardiogram), which is similar to the scan which most mothers have during pregnancy. This test is not painful and involves no risk. Some children may need to be sedated with a mild medication so they can lie still to obtain the test results. With an echocardiogram, it is often possible to make a very precise diagnosis of the nature and severity of the heart problem. The test takes between 15 minutes and 1 hour to perform. Sometimes, especially with more complicated heart problems, the test may need to be repeated several times to obtain complete information.

If the baby has symptoms of heart failure in the early months of life, further investigations may be required. The object of these investigations is to confirm the diagnosis and to obtain detailed information about the heart abnormality and its effects on the lung circulation. This information cannot be obtained by other means.

In many cases, especially where there is no evidence of strain on the heart, such tests may not be necessary or may be postponed until the child is older. They may often be carried out as part of the preparation for an operation.

## **What is meant by cardiac catheterisation and interventional procedures?**

The term 'cardiac catheterisation' refers to the passage of a fine tube (called a catheter) into the heart chambers through a vein, or an artery, usually from the top of the right leg just below the groin. By this means, blood samples and pressure measurements can be obtained from within the various chambers of the heart. This provides much information about the effects of the heart problem on the function of the heart and on the lung circulation. Usually, XRay dye is injected to obtain pictures of the heart chambers and vessels (angiocardiology). These tests are only required when adequate information cannot be obtained by other methods (e.g. echocardiography), or when the cardiologist advises that the heart problem needs special treatment involving heart catheterisation (called an 'interventional procedure'). Procedures of this latter type may be used to stretch open a narrow valve or blood vessel, using a catheter with an inflatable balloon. Alternatively, a tiny 'spring coil' may be inserted to block off an abnormal and unwanted blood vessel, or an expanding plug (usually referred to as a 'device') may be placed to close a hole such as an ASD or VSD.

A general anaesthetic will usually be given for these tests or procedures. The child will normally be admitted to hospital on the day of the test and discharged a few hours after it. Arrangements will be made to discuss the initial results of the test with the parents on the day of the procedure. The final results will often need to be discussed in conference (e.g. with the heart surgeons) before making decisions about further management, and so may not be available for several days.

The skin puncture, through which the catheter is inserted, does not usually need stitches, but there is often some bruising which will leave some soreness for a few days. Otherwise, there should be no ill effects after the procedure, though the anaesthetic may lead to nausea or vomiting for a few hours, and general tiredness for a day or two in some individuals.

## **What does heart surgery involve?**

If an operation is thought to be necessary, one of the Cardiac Surgeons will discuss the proposed surgery with the child's parents. Sometimes, an operation will be needed urgently in the first few weeks after birth. When there is no major urgency, the operation will usually be performed at the earliest stage with the lowest possible risk, and well before there is likely to be any irreversible damage to the heart, lungs or other organs as a result of the heart problem. This is likely to be within the first one to two years of life in most cases, unless the problem is detected later or does not merit an operation until an older age. Until this time is reached, periodic reviews will be carried out so that any change may be detected and plans altered if necessary.

Children undergoing heart operations usually stay in hospital for about one week, though young infants and some older children may need to stay longer. School age children may then require a few weeks further convalescence at home.

A number of the conditions which require an operation can be dealt with by fairly simple methods. Others can only be dealt with using the heart-lung bypass machine (so called 'open heart' operations). This machine will take over the work of the patient's heart and lungs while the surgeon operates inside the heart itself. Operations with the heart-lung machine involve different (though not necessarily higher) risks than those for which the machine is not needed. Particular problems relating to individual cases will be discussed with parents when surgery is being considered for their child.

## **Will my child be in pain after surgery?**

It is likely that your child will experience some degree of pain after surgery. Each child has their own pain threshold and will communicate their level of discomfort to you as best they can. Your child's pain can be controlled, and you are encouraged to discuss this with the nursing staff or the doctors who are caring for your child.

Immediately after open heart surgery, while your child is in the intensive care unit (ICU) and when their breathing is being assisted with a respirator, both a strong pain reliever (morphine), and a muscle relaxant will be given through an intravenous drip. The muscle relaxant is given to the child to prevent movement of limbs or attempts to breathe against the respirator, so that the heart can rest as much as possible in the early post-operative period. This medication is gradually reduced as heart function improves and while the child is being weaned from the respirator. The child would normally remain on some morphine until transferred to the cardiac ward. At this stage, the morphine is gradually reduced and replaced with paracetamol (usually Panadol).

Paracetamol may be given either as an oral liquid or tablet, or as an anal pessary. It is routinely given every four hours and gradually reduced to six hourly doses by the time the child is ready to go home.

If at any time you feel that your child is not coping with their pain, please feel free to discuss this with the nursing staff.

## **Will my child need a pacemaker?**

A pacemaker is a device used to keep control of heart rhythm and rate, if the heart cannot control its own rate or rhythm adequately. Many infants and children experience temporary problems with their heart rate or rhythm in the early period after surgery. Therefore a temporary pacemaker is usually attached for a few days. The pacemaker wires (which connect the device to the heart) are sewn to the outside of the heart at the time of an operation and emerge through the skin to be attached to the pacemaker, which remains outside the body. These wires will be removed after a few days, when the heart rhythm is normal and the child is recovering. The wires can be pulled out without reopening the wound and this does not damage the heart.

In a few children there may be a need to fit a permanent pacemaker. This is connected to the heart with one or two wires (a much longer lasting equivalent of the pacemaker wires referred to above). The wires may be introduced either through a vein (and then attached to the inside of the heart), or at an operation (if they need to be connected to the outside of the heart). The pacemaker itself varies in size from a very tiny unit (the size of a twenty cent coin), which can be used for small babies, up to something more like a small pocket watch. The device may be placed under the skin in the upper abdomen or in front of an armpit. The batteries in these pacemakers last for many years. The pacemaker, its wires and battery all need to be checked regularly (normally every six months) at an outpatient appointment. They will need to be surgically replaced if faulty.

## **Can there be complications from heart surgery?**

Complications from surgery may arise, but with improvements in technology, in surgical procedures and with more surgery being performed at a younger age, the risk of complications is continually being reduced.

The possible complications are related to the specific type of surgery being performed and they vary widely depending on the nature of the problem which requires surgery.

Your child's cardiologist and cardiac surgeon will discuss this subject with you prior to surgery.

## **Will my Child be considered for a heart and/or lung transplant?**

In a small number of children with severe heart problems, the doctors may discuss the possibility of a heart and/or lung transplant. There are many important aspects to the doctors' decision to recommend a transplant. This procedure cannot be guaranteed as a long-term cure. The family will require extensive counselling before the decision is made. The hospital has a transplant coordinator who works with the cardiologist and surgeon. Together they will provide detailed information on the heart and/or lung transplant. The family will be provided with time for full discussion with the transplant team.

## **Is blood transfusion necessary?**

Blood transfusion is required for many children who have heart surgery and sometimes for other reasons. Blood contains a variety of components, including the red blood cells which carry oxygen, proteins in the plasma and a number of special factors which are necessary

for blood clotting to take place (e.g. platelets, fibrinogen, factor 8, etc.). These components are sometimes given separately, e.g. platelets or plasma, where there is a problem needing treatment with specific blood products. It used to be thought that every child having heart surgery (especially open heart surgery) would need a blood transfusion. Nowadays, with much improved heart-lung bypass equipment, this is not always the case. In young children (up to two or three years old) it is usually desirable to use blood products, as they may become severely or dangerously anaemic without them. In older children, depending on the complexity of the procedure and the amount of blood which they are likely to lose during the operation, it is often possible to manage without transfusion and when feasible, this is now the preferred option. All children will have their blood cross matched before surgery so that it is available if required.

The blood is provided by the Red Cross Blood Bank and is carefully screened. The provision of blood by families of children undergoing heart operations (for use in their individual child) is not usually possible. Donor screening procedures prevent the transfusion of blood from new donors until several months after their initial screening tests. This ensures that the tests can be repeated twice, at a time interval of several months, before blood (taken after the second round of testing) is actually transfused into a patient. However, recruitment of new donors from families of patients is helpful, and facilitates greatly the valuable work of the Red Cross Blood Bank throughout the community. Those wishing to become blood donors should contact the nearest Red Cross Blood Bank.

### **How can I prepare for my child's hospital admission?**

Children who are old enough to understand, should be given some appropriate explanation of the hospital admission. Several days prior to admission, you may wish to contact ward staff for a guided tour of the hospital and its facilities. It is advisable that when preparing your child for a hospital stay, you answer their questions truthfully according to their ability to understand and cope with the information. Children need to know that they will be staying in hospital and that they will be coming home afterwards. It may help to tell them that you will visit as much as possible. Please allow them to bring their favourite books, etc. to hospital. They may wear their own pyjamas and clothes while in hospital or wear those provided by the ward. You may like to bring a camera and diary to record your child's progress in hospital, and to help you answer questions from family and friends. If bringing items from home, please ensure they are clearly named. Do also remember that any siblings need to be included in these preparations.

Parent accommodation may be available at your Hospital, or nearby if you require it. If there are difficulties about the cost of transport to the hospital, or about accommodation for parents please contact the social worker attached to the Cardiac Unit prior to admission, or your HeartKids Family Support Coordinator for help if possible.

Children will usually be admitted a day prior to their operation, or on the morning of surgery. It may be necessary for families to attend on the previous day for routine last minute investigations, e.g. for taking blood samples for cross matching blood type. Information will be given about fasting and whether medication should be temporarily ceased.

An admission date can usually be arranged to suit both the family and the surgical team. If, when the time comes for admission, the child has a cold or there are other problems, it is

best to contact directly the consultant medical staff (surgeon or cardiologist) or their registrars at the hospital to discuss the problem. It is more satisfactory to do this than simply to leave a message at the hospital. It would be appreciated if this was done before the day of admission if possible, as this would help considerably in making alternative arrangements.

It is desirable that both parents be available at the time of their child's operation. Arrangements will be made with them about where they should wait during the surgery. When possible, the surgeon will speak to the parents after the operation has finished. For a day or two after the operation, the child will usually remain in the intensive care area. This will be a time of recovery from the immediate effects of the operation. They will then be transferred to children's ward for further recovery. Parents are usually welcome to visit or stay with their child in the ward at any time. While their child is in hospital, parents should tell ward staff of their whereabouts and at what times they are able to visit.

## **What are some of the costs of my child's medical care?**

### *In Hospital - Public Patients*

There will be no charge for any inpatient or outpatient service given to public patients who are covered by Medicare.

### *In Hospital - Private Patients*

There will be charges for these patients as determined by the conditions of admission of such patients to the Hospital. Professional charges (e.g. surgeon, pathologist, anaesthetist) will be levied at the rate determined by Medicare's scheduled fee. Medicare will reimburse at the appropriate rebate, with the gap being covered for inpatient services, by your private insurance. Hospital charges (e.g. accommodation, theatre fees) are set at the standard rates for public hospitals and will be reimbursed by your private insurance.

Outpatient services are not covered by private insurance, but Medicare will reimburse professional charges to the amount of the rebate for outpatient services (currently 85% of schedule fee).

### *Pharmacy*

If you are a holder of a Health Care Card, NHS (National Health Scheme) prescriptions will cost significantly less than the full price charged to other people.

### *Ambulance*

From time to time, patients may need to be transported to or from the hospital by ambulance. The full charges for this can be substantial, but may be covered in your state by various schemes. These may cover charges incurred in transport, when warranted by the child's condition, to and from a hospital, or from one hospital to another. Families living in country areas should subscribe to their local ambulance service, and also ensure that they are covered for air ambulance costs in case the need for air transport arises. Subscriptions for the Metropolitan Ambulance Service may be fully recoverable from private health insurance organisations. If the child is the holder of a health care card, or if the parent has a pension card, then the service is free.

### *Accommodation*

If you live outside of your metropolitan area you may be eligible for assistance from your

State Government in the form of a rebate to help with the cost of petrol and accommodation. Please check with your hospital social work department.

### *Child Disability and Carer Allowance*

Centrelink pays a fortnightly amount to families of children who require extra care. The extra care involved must be substantially more than is needed by a child of the same age without a disability.

Recipients of the Carer Allowance also receive a health care card for that child which enables prescriptions to be purchased at a significantly lower cost. Those not eligible for Carer Allowance, may be able to apply for the carer payment.

For more details on the benefits and how to apply for the allowance please contact your local Centrelink office.

Some families may also be eligible for an RTA mobility parking sticker, if their children cannot walk long distances.

## **Where can I obtain further information?**

If at any time parents are worried about their children, or have further questions, they should not hesitate to contact their cardiologist, their HeartKids Family Support Coordinator or the social worker attached to the cardiology department. Some parents have found it helpful, when attending appointments, to take another adult who can also listen, take notes, or help mind their child.

Many hospitals will have a **Child Health Information Centre**. These centres provide books, pamphlets and articles on a wide range of topics to help parents and children understand more about child health and hospitalisation.

When your child is diagnosed with a heart condition (congenital or acquired), it is natural to be upset and shocked. You may have feelings of fear, anger, guilt or a deep sense of loss. Questions may arise, such as - 'Why us?' 'What did I do to make this happen?' 'Can I cope?' 'What does the future hold?' All of these feelings and reactions are normal.

Everyone needs time and support when coming to terms with any major illness. The HeartKids parents have found that talking to someone who has been in a similar situation can be of help.

Doctors and medical staff will manage the treatment of your child's heart problem. HeartKids' role is to provide non-medical support and understanding.

Through HeartKids activities, all members of your family can meet with others, share experiences, learn more about their child's condition and perhaps find some friends with whom they share a bond.

For further medical information specific to your child's heart condition, you are encouraged to speak to your child's cardiologist, general practitioner or paediatrician. Even when children have the same diagnosed condition, there can be individual variations between them. They may also respond differently to surgery, medication, exercise, etc.

**Written with the assistance of Dr Jim Wilkinson, Director of Cardiology, Royal Children's Hospital, Melbourne Australia and Margaret Patullo – HeartKids Victoria.**