

# Heart Disease

## Overview

The majority of children with a heart disease have been born with it. This is called congenital heart disease and mostly develops during pregnancy. The disease usually involves a disorder of the heart itself, the heart valves, major arteries or a combination of these.

Congenital heart defects are the most common birth abnormality, affecting one in every hundred children. Each year over 2000 children are born with heart defects. They are still the greatest cause of death in children under the age of 5. In about 20% of cases the cause has some genetic link, but for the other 80% the cause is largely unknown.

## Congenital Heart Disease

This is by far the most common form of childhood heart disease and can present itself in many ways. There are a wide variety of heart diseases that can vary from minor holes in the heart through to a complex range of conditions. In about half the cases the child will need ongoing medication or surgery.

A full list and description of the most common congenital heart diseases is available on the website [www.heartkids.org.au](http://www.heartkids.org.au)

## Acquired Heart Disease

Some children may acquire heart disease. These may include

- Rheumatic heart disease, a condition where the heart valves have been damaged by rheumatic fever. Rheumatic fever is not contagious and often caused by simple things such as untreated strep throat or skin lesions. It is extremely common in indigenous communities, with Australia having the highest incidence in the world.
- Kawasaki disease a condition that mostly affects children under the age of five years. It occurs when there is an inflammation of the coronary arteries that supply blood to the heart resulting in damage to these arteries. As a consequence, the child may be more susceptible to stroke or heart attacks in later life. The disease is not contagious to other children.
- Cardiomyopathy is a condition where the heart muscle becomes inflamed and is unable to function properly. Often cardiomyopathy is as a result of a viral infection. In severe cases a child will need a heart transplant to address this.

Symptoms of heart disease vary and present differently for each child. As a result, diagnosis may occur shortly after birth or not for months or years, and may even not occur until adulthood.

## Treatment

Treatment depends very much on the type of defect the child has, how serious the heart defect is, and the impact of the disease on the child's daily life.

Medication may be able to rectify the problem for some children, but many will require surgery to correct the defect at some point in time. Some children will need careful monitoring as treatment may be necessary at a later stage.

Some treatments for heart disease may involve the child staying in hospital for a period of time and having medication or one or more operations which will either improve the heart's function or correct the abnormality. Most children with simple heart defects survive into adulthood, although their capacity to exercise may be limited.

## Parents Information

Some of the important things you can do as a parent include:

- Inform your child's school about his/her medical condition.
- Ensure all information is available and recorded in your child's school health plan and ensure it is updated regularly and the LST / PSG advised of any changes to treatment protocols.
- Plan medical appointments to minimise the disruption to learning.
- Notify the teacher/s if your child is having disruptive sleep patterns as a result of their illness. He/she may be tired and lethargic at school and their behaviour may be different.
- Be mindful that your child may encounter some difficulty with concentration or learning at school. This can be as a result of oxygen deficiencies as a result of their condition or as a side effect of open heart surgery.
- Whilst many children will learn just as other children do, there is a percentage where these issues will be present. Parents should discuss and monitor this with their child's teacher.
- Seek information about support services for you and your child.
- Ensure your child knows about their condition and what it means in relation to exercise and other school activities.
- Encourage your child to exercise regularly to maintain their general health and wellbeing within the medical guidelines or advice.

## Issues

- Some children will encounter difficulty breathing and become breathless after physical exertion
- Many will need to take medication on a regular basis.
- Some children may encounter some difficulty with concentration or learning at school.
- Some children will have a susceptibility to bruising or bleeding more easily than other children and will need to avoid contact sports – the child's paediatrician will recommend what physical activity the child can undertake.
- Some children may present as being 'blue' in appearance. This is as a result of oxygen deficiency and will need to be monitored closely. These children are susceptible to the cold.

## School /Teacher Information

- Depending on the severity of the heart condition the student may need to minimise certain physical exertion. Under no circumstances should these children be forced to complete the same physical activities as other children (unless agreed by their parents and doctors)
- Be aware that some children may encounter some difficulty with concentration or learning at school as a result of their condition or surgery.
- Ensure all specialist teachers are briefed on these children to ensure constant care.
- If they become tired or breathless during the school day they should be allowed to rest and monitored closely.
- Monitor ventilation in student's classroom.
- Seek immediate medical assistance if the child presents as overtly unwell or complains that they are not as they should be. The causes of this could be many and varied.
- Monitor the student during physical activities, especially a child who may have a severe heart abnormality. Ensure they are participating at the level agreed in their IEP.
- Provide as many opportunities as possible for the student to demonstrate areas of strength while at school e.g. a student may not be allowed to participate in cross country, but they may act as official photographer of the event.
- Additional information and resources are available from HeartKids Australia. [www.heartkids.org.au](http://www.heartkids.org.au)