

# LIVING LIFE WITH HALF A HEART

When you are first told that your baby has a heart problem it is very difficult to know what sort of life your child will lead. This section of the filofax hopes to answer some of the most commonly asked questions about life at home.

It is extremely important to remember that each child is different and that not all of the information below will necessarily apply to your child.

## Appearance

Children with heart disease look very normal. They may have a slightly blue tinge around the lips and fingernails (cyanosis). This is because they have a reduced amount of oxygen flowing around their bodies. After the final operation when the blue (deoxygenated) blood and the red (oxygenated) blood have been separated, they should be pink.

## Development

Children who recover well after surgery will normally be able to crawl, walk and run as children of their age will do, although they may become tired on exercise more easily. They should go to normal school and be able to take part in normal learning but they may find concentrating for long periods difficult and the physical parts of school life challenging - some children need extra support in school to help them reach their full educational potential. Socially the children will be able to develop normal friendships and take part in normal family life.

## Diet and growth

Children with heart disease need more calories than other children. Their hearts need more energy to function so they need to take in extra calories if they want to grow. During the first few months of life especially, the child will need regular weight checks to ensure that their food balance is correct.

If they are not gaining weight then more calories will have to be added to their milk. If they are tiring easily whilst feeding (*see section on Heart Failure*), it may be necessary to rest them temporarily by feeding them down a tube that has been passed into their stomach. For many babies it is normal to need some sort of help to gain weight. The hospital dietician and the community health visitor will be available for information and support.

## Activity

Children with complex single ventricle disorders can walk and run. They should be able to ride a bicycle and play football in the back garden, but they will not be able to play a full game of football or run in a competitive race as they will tire easily. Contact sports are not possible because of surgical scarring and anti-coagulation treatment.

## Long-Term Treatment

If the surgery has been successful the children should not need to spend a great deal of time in hospital. They will need to have regular outpatient check-ups to monitor their progress, with the occasional hospital admission for tests.

Most children are on some of the drugs described in the section on Commonly Used Drugs, but these are given at home and the children become used to having them.

# THE FUTURE

When planning the treatment path for children born with half a working heart, it is important to look at the quality of life that they may be able to attain.

The advancements in surgery have enabled many children to enjoy life, joining with their peers in their education and play. They may have to learn to compromise on physical activity but they are able to lead full lives; some have even gone on to have families of their own.

However for some, the heart will gradually tire and begin to fail despite treatment. It may be that transplantation will be the treatment of choice at that time.

If you would like more information on treatment changes or you would like to be able to talk with the parents of children with these complex disorders contact the **Little Hearts Matter** team on **0121 455 8982**.