

## Checking your baby's heart

You have been given this sheet because your child has a heart murmur.

### A heart murmur

A 'murmur' is the word used to describe extra sounds that blood makes as it passes through the valves and blood vessels of the heart. Nearly all new born babies have murmurs, because the foetal system closes down gradually in the first few hours/days of life, meaning that blood is still circulating through this now obsolete system.

Many babies and children have murmurs until they reach puberty - these are called 'innocent' murmurs, caused by the normal workings of the heart.

An unusual murmur in a newborn or a murmur that can be picked up when the child is older could mean there is a heart disorder. For example the sound could be made by blood crossing through a hole, or a valve that is too narrow.

There are many other disorders of the heart which can cause murmurs - many are minor and need no treatment, some may need medical procedures which can cure the problem without surgery, and in some cases the child may need heart surgery in the shorter or longer term.

### The tests

Your child will be seen by a cardiologist, and if he or she is not satisfied that the murmur is normal, a detailed diagnosis can be made very quickly with modern echocardiogram machines.

You will normally have to travel to a Paediatric Cardiology Unit to have this diagnosis made. Most tests are not

painful, but be prepared for a lot of squirming and holding on tight with younger ones. Toddlers and older children sometimes find tests, like scans and ECGs, frightening. Although this is distressing for you, stay calm. Ask if the test was completed satisfactorily, or do you need another appointment.

Tests can include:

**Weighing** - take a note of the birth weight with you in kilos

**An echocardiogram** - like the one you may have had in pregnancy only looking at the child's heart this time

**An ECG** - leads placed on the child and a reading taken of the electrical activity of the heart

**Sats test** - looking at the amount of oxygen in your child's blood by using a clip on the finger, ear or toe

**Chest x-ray** - sometimes needed to look at the position of the organs in the chest.

### Preparing for your visit

The cardiologist will also look at the child to see if he or she is showing any signs of heart disorder - such as blueness or breathlessness. You will need to be prepared to answer questions about your child's feeding and sleeping habits.

In some conditions the child will need further tests as an in-patient. Rarely the child may be taken into hospital straightaway for further tests or treatment - this is very unlikely if he or she is not causing you any other health concerns.

### Take someone with you

If you are someone who likes the support of other people, and your partner can't make it, try and take a relative or friend with you. If all is well, it is someone to celebrate the good news with. If not, you may find it helpful to talk it over straight away with a person to whom you and the child are important.

### How serious is it?

If your child has a heart disorder, you should be able to ask any question you like of the doctor. At this point you will be told how serious the disorder is:

- Some heart problems are not life threatening and can be dealt with quite simply
- Some conditions - such as when a child's heart is beating in the wrong rhythm - can be helped by medicine
- Other conditions could mean surgery which can mean a complete recovery
- And there are a few conditions which can mean an uncertain future for the child.

### Write it down

Of course, even if you feel prepared, the shock of hearing that your child has a heart disorder can make it very difficult to take in information clearly. So before you leave try and do the following:

- Write down the telephone number and names of the people you have seen.
- Ask what they will be telling your GP and how - by telephoning, fax or letter.
- Ask if there is a specialist counsellor attached to the Centre and how to contact them.
- Get the name of the disorder written down. You may want a diagram as well - most of us haven't taken an interest in the workings of the heart before and need it explained simply.

If you feel in need of someone to talk to, call the children's heart federation on 0808 808 5000.

We can send you information about bringing up a heart child and put you in contact with parents and support groups who know what it is like to have this diagnosis made

### Your notes

<b>Name of Cardiologist:</b>

<b>Address and telephone number of the Paediatric Cardiac Unit:</b>

<b>Other people you may need to speak to:</b>

<b>Date of any other appointment:</b>

Please contact CHF if you have suggested amendments or changes as we like to keep our information sheets relevant and up-to-date.

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