

# HOW THE DIAGNOSIS OF SINGLE VENTRICLE HEART DISEASE IS MADE

There are two times to make a diagnosis of complex heart disease - either before or after birth.

## **Antenatal Diagnosis**

In many cases it is now possible to make a diagnosis of a single ventricle condition when pregnant women undergo their 16-20 week ultrasound scan. It is usually at this time that the heart and other organs within the baby are big enough to be seen clearly.

A radiographer/sonographer, who will be looking to see that the baby's heart has four chambers, usually does this scan. If there is any doubt that the baby has normal organs the radiographer will seek a second opinion from the obstetrician or fetal medicine doctors (doctors who specialise in looking at unborn babies).

If a problem with the heart is seen clearly the obstetric team will refer the family to a specialist in this field, a fetal cardiologist (this is a heart doctor who specialises in looking after unborn babies). If a complex condition is confirmed, the cardiologist and the obstetric team will talk to the family about the diagnosis and the possible treatments. They will offer further tests, such as amniocentesis, to see if the baby has any unseen problems with their genetic picture (to see if the blueprint of the baby has a fault - for example something like Down's syndrome). *For more information on antenatal tests speak to your midwife.*

Once all the tests have been completed the family will be given the opportunity to discuss the future for their child. The team will support the family whilst they make their decision either to continue with the pregnancy or to end the pregnancy through termination.

Most babies with a single ventricle condition grow well in their mother's womb. They are usually born between 38 and 40 weeks. It is only after birth, once their fetal circulation changes (*see section on Fetal Circulation*) that their defects begin to affect their bodies.

*For more information please refer to the Antenatal Information pack.*

## Postnatal Diagnosis

As long as the Ductus Arteriosus remains open, it is often difficult to detect that a newborn baby has a problem with its heart. *See Fetal Circulation.*

As the Ductus Arteriosus closes the baby will become breathless and sweaty, they sleep more and drink less milk. This can happen while the baby is still in hospital or within a few days of going home. The midwife or health visitor should notice that the baby needs to see a doctor.

Once the baby has been referred to a paediatrician (baby doctor) tests will be done to try and find out what is causing the problem. Medicine called Prostaglandin will be given to the baby to try and keep the Ductus Arteriosus open, as it is this that will keep the baby alive until treatment decisions can be made. *See Fetal Circulation.*

The baby will be transferred with a medical team to the nearest hospital that treats congenital heart defects. Here the baby will have an ultrasound scan (Echocardiogram) similar to the scans done in pregnancy. The specialist heart team will be able to see what the heart looks like and will be able to make a diagnosis.