

Visiting Your Specialist Centre

Depending on where you live, you may have to travel some distance to your nearest specialist centre. Some cardiac conditions are very complex making the appointment lengthy as they include a scan followed by counselling.

This means that there could be a wait to be seen once you have arrived. There are different types of heart conditions and they vary in seriousness and need to be looked at individually.

Some less serious conditions include holes in the heart, which mean that once the baby is born, the hole allows oxygenated and deoxygenated blood to mix. Other more serious conditions, known as critical congenital heart disease (CCHD), can occur when the heart hasn't formed correctly, and the baby may need medication or surgery soon after birth or within the first year of life.

At your specialist appointment, you will be scanned again to confirm whether your baby does have a heart condition. You may be scanned by more than one person and there is often more than one health professional in the scan room.

Sometimes, on-screen findings are discussed during the scan and there is often lots of medical terminology used, but everything will be explained to you at the end of the scan.

Sometimes, the specialist scan finds that the baby's heart looks structurally normal and is working well, and no more tests are needed.

People you may meet at your appointment

Below is a list of some of the people you may meet at your appointment:

- Consultant
- Paediatric cardiologist
- Consultant in fetal-maternal medicine
- Neonatologist
- Specialist/consultant sonographer
- Cardiac physiologist
- Cardiac liaison nurse
- Midwives
- Health care assistants
- Medical students
- Student midwives
- Sub-specialists in fetal medicine
- Depending on extracardiac involvement – genetics, general surgeon, neurosurgeon, urologist
- Palliative care team
- Cardiac nurse specialists

Once a cardiac diagnosis has been made, you may be moved to another room (a quiet room or a counselling room) where the cardiologist and/or obstetrician will inform you about the result of your scan and what this will mean for your baby.

They may do this with the aid of diagrams, describing how your baby's heart is formed and how it is functioning.

There is no single cause for congenital heart disease (CHD) and often we do not know why it happens. CHD is a condition which usually occurs during the baby's early development. Parents often ask if there was something they did or did not do which caused the heart condition. The answer to this is usually 'no'.

Some heart defects can be linked with other conditions such as chromosomal or genetic conditions and you may be offered the choice of having an amniocentesis test to determine if this is the case for your baby.

This link, from the NHS website, will tell you all about the amniocentesis test:

<https://www.nhs.uk/conditions/amniocentesis/>

Sometimes, the amniocentesis can be done on the same day at the specialist centre, although, you do not need to make any decisions on the day. Only you know what the best decision for you and your family is.

You will be given a written report with a diagnosis on it. The report will also contain a plan of care for the rest of your pregnancy, delivery and after baby is born.

Babies with less serious heart conditions will be able to be born at their local hospital.

Babies with critical CHD need to be born in a maternity unit with a neonatal intensive care unit (NICU) on site. This is because the baby will need specialised medical or surgical care in a unit that is experienced in caring for babies with CHD.

You may be offered a chance to look around the NICU and also visit the paediatric surgical unit.

The specialist unit may suggest follow up appointments to scan you again later in the pregnancy. This will be to keep a close watch on how your baby's heart is growing and functioning.

Contact details of the cardiac liaison nurse specialist will be given to before you leave should you have any further questions.

Tiny Tickers is here to help you and your family when you receive a diagnosis of congenital heart disease. Our website – www.tinytickers.org – has lots of information, advice and support for heart families.