

Brain development in babies with congenital heart disease

This leaflet explains about brain development in babies with heart problems. You have been given this leaflet because we have confirmed that your baby has a heart problem (also called congenital heart disease). If you have any more questions or concerns, please speak to a doctor or nurse caring for you.

How congenital heart disease could affect your baby's brain

This is a complex subject that is not yet fully understood. There is currently limited evidence available on how many children born with heart disease have brain development problems. The overall scientific knowledge about this area is limited and more detailed research is needed.

Any child, with or without heart disease, can have learning difficulties or behavioural problems as they grow up. Children can have a wide range of possible difficulties, such as:

- an impaired memory
- problems in expressing themselves through language
- problems in understanding the language of others
- a low attention span or difficulty in concentrating
- poor planning abilities
- poor impulse control, which means acting rashly without thinking about the possible consequences

These issues can lead to problems with social interaction and behaviour in later life.

Most children with congenital heart disease:

- do not have an obvious extra problem with their brain development
- can manage their schoolwork

However, some children are more likely to have learning difficulties and behavioural problems than the general population. The more serious the heart problem, the more likely it is that children will have these issues. It is difficult to give specific statistics because there are not yet enough clear scientific data.

Why children with congenital heart disease are at increased risk

This is a complicated topic, which is also not fully understood at present. There are many things that can affect how the brain develops, such as if your baby:

- has a genetic problem
- has problems with the blood flow to their brain
- is born early
- needs heart surgery soon after birth

The fetal cardiology (heart) team may be able to give you more information that is specific to your baby. However, we can never be 100% certain about how a baby's brain will develop.

When your unborn baby is diagnosed with congenital heart disease, we have a duty to explain the increased risk of brain development problems. This forms part of a counselling session with the fetal cardiology team, where we talk about all aspects and implications of the diagnosis.

What tests are available

We cannot say with confidence which babies will have problems with brain development or predict accurately how serious these problems might be. There are no tests that we can do before birth to predict if your baby will have problems with their learning or behaviour. However, we do know generally that babies with congenital heart disease as a group are at increased risk.

Some genetic problems can be diagnosed before birth. However, the tests do not tell you how mildly or severely the baby will be affected. Scans before birth can look at the structure of your baby's brain, but do not show how the brain works.

What treatment is available

At the moment, there are no specific treatments available to:

- help with brain development before birth
- reduce the chance of problems with learning or behaviour after birth

What you can do to help

We recommend that you follow your midwife's general guidance about keeping well in pregnancy. There are no specific things that you should do to protect your baby's heart or brain while you are pregnant. Your midwife and fetal cardiology team can give you more advice about this.

Useful information

The following websites have more useful information about the issues in this leaflet:

British Heart Foundation

Web www.bhf.org.uk/information-support/conditions/congenital-heart-disease

Evelina Children's Heart Organisation (ECHO)

Web www.echo-uk.org

NHS

Web www.nhs.uk/conditions/pregnancy-and-baby/nhs-pregnancy-journey

Contact us

If you have any questions or concerns about your baby's heart, please contact the fetal cardiology team, **phone:** 020 7188 9201, Monday to Friday, 9am to 5pm

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web** www.evelinalondon.nhs.uk/leaflets



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