

Craniosynostosis

Information for patients



Leeds
Maternity Care

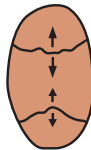
This leaflet is aimed at pregnant women with an unexpected finding of craniosynostosis on ultrasound examination. The leaflet should only be supplied in supplement to a consultation with a senior obstetrician / fetal medicine specialist.

What is craniosynostosis?

Craniosynostosis is a rare condition which causes a baby to be born with, or to develop an abnormal head shape. The bones of a baby's skull usually have small gaps between them to allow the head shape to change during birth and to allow the skull to grow to make space for the brain as it increases in size. In craniosynostosis, one or more of these gaps or sutures, closes or fuses earlier than it is meant to. This causes the head shape to become abnormal as the rest of the skull bones continue to grow.



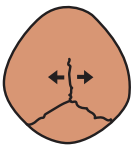
Synostotic trigonocephaly



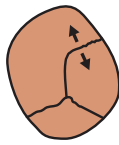
Synostotic scaphocephaly



Normocephaly



Synostotic brachycephaly



Synostotic anterior plagiocephaly



Synostotic posterior plagiocephaly

Why has it happened?

In most babies where only one suture closes early, the cause is unknown.

In a small number of babies, when multiple sutures close, the cause is more likely to be genetic, i.e. due to a fault in one of the baby's genes and other problems may be associated with the underlying condition or syndrome.

What does it mean for my baby?

Before birth

In some cases, craniosynostosis occurs in a baby because of a genetic or chromosomal problem. If other problems are identified on the ultrasound scan, you may be offered a test called a CVS or amniocentesis to test the baby's genetic information. (See separate leaflet.)

Some genetic or chromosomal problems may have an impact on a baby's development and wellbeing.

After birth

In simple single suture craniosynostosis the baby may require a straight forward operation for cosmetic reasons at some point in their childhood.

In more complicated cases, where other bones can be involved e.g. the facial bones or the hands and feet, there can be other problems which are less easily treated.

- Problems with the facial bones can affect the child's ability to breathe

- Problems with the growth of eye sockets can affect the way the eyes are protected and the way that they work
- Lack of space for the growing brain can cause a build-up of fluid “hydrocephalus” which may need draining

Regardless of the type of synostosis, your baby will be referred to one of the expert centres. The nearest centres for the treatment of these types of conditions are in Liverpool and Birmingham.

We may advise that you see meet with one of the local craniofacial consultants and one of our genetics consultants before your baby is born, to talk about what to expect after birth.

What happens next?

Your local hospital obstetric team will discuss your case with the Fetal Medicine Unit specialists at Leeds Teaching Hospitals. You will be offered an appointment for a detailed ultrasound scan and a discussion with a fetal medicine specialist.

If additional problems are identified on the scan, you will be offered a needle test (CVS or amniocentesis).

Where else can I find help?

Be sure to ask questions to the doctor supplying you with this leaflet and make a note of any questions you would like to ask at your Fetal Medicine Unit appointment. Your local hospital will also have a specialist midwife who you will be able to contact for further discussion.

Other useful sources of information:

Antenatal Results and Choices

- www.arc-uk.org

Headlines

- www.headlines.org.uk



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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Developed by: The Fetal Medicine Team

Produced by: Medical Illustration Services

MID code: 20200428_020/MH

LN001772

Publication date

01/2021

Review date

01/2023