



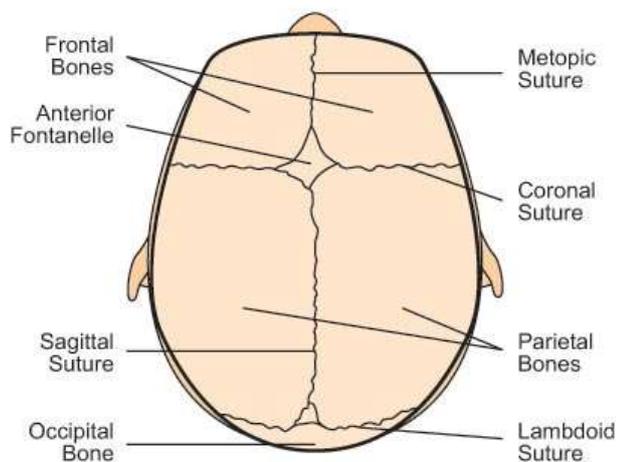
Great Ormond Street Hospital for Children NHS Foundation Trust

# Sagittal craniosynostosis: information for families

**Sagittal craniosynostosis (also known as scaphocephaly) is the most common type of non-syndromic craniosynostosis and occurs when the sagittal suture fuses before birth. This information sheet from Great Ormond Street Hospital (GOSH) explains the causes, symptoms and treatment of sagittal craniosynostosis.**

The skull is made up of several 'plates' of bone which, when we are born, are not tightly joined together. The seams where the plates join are called 'sutures'.

## Normal Skull of the Newborn



As we grow older, the sutures gradually fuse (stick) together, usually after all head growth has finished. When a child has craniosynostosis, the sutures fuse before birth. It can affect one suture or several.

In sagittal craniosynostosis, all or part of the sagittal suture fuses before birth, leading to the skull being long from front to back but narrow from side to side.

Sagittal craniosynostosis is also known as scaphocephaly – from the Greek for boat-shaped. It is rarely associated with problems affecting other parts of the skull, face or body. Sagittal craniosynostosis seems to affect more males than females but we are not yet sure why this should be the case.

## What causes sagittal craniosynostosis?

The cause of sagittal craniosynostosis is not yet known. There may be a genetic basis to the condition as it seems to be passed on from parent to child in a small number of families but the gene affected has not been identified. Some people believe that the cause of sagittal craniosynostosis is the position of the baby while in the womb altering the head shape. More research is needed to identify the cause of sagittal craniosynostosis.

## What are the symptoms of sagittal craniosynostosis?

The main sign of sagittal craniosynostosis is a bony ridge over the prematurely fused sagittal suture. Depending on whether the entire sagittal suture has fused or only part of it, children have a strong forehead and the back of the head (occipital region) is also quite prominent.

The two problems that can be associated with sagittal craniosynostosis are speech and language delay and raised intracranial pressure. Some children with sagittal craniosynostosis tend to start to speak later than other children but with help from a speech and language therapist they usually catch up. Raised intracranial pressure seems to develop in a very small number of children between the ages of three and five years. We are not sure why this happens, but it seems to occur whether or not a child has had skull re-shaping surgery.

## **How is sagittal craniosynostosis diagnosed?**

As children with sagittal craniosynostosis have a characteristic appearance, no specific diagnostic tests are needed. Imaging scans, such as x-ray or CT, may be suggested to monitor bone growth before, during and after treatment.

As the gene mutation causing sagittal craniosynostosis has not yet been identified, genetic testing is not helpful in most cases but when possible we like to investigate all forms of craniosynostosis.

## **Further information and support**

Headlines – the Craniofacial Support Group – is the main support organisation in the UK for families of children and young people affected by a craniofacial disorder. Visit their website at [www.headlines.org.uk](http://www.headlines.org.uk)

Changing Faces is another organisation that offers help and support to anyone living with a condition that affects their appearance. Visit their website at [www.changingfaces.org.uk](http://www.changingfaces.org.uk) or telephone their helpline on 0845 4500 275.

## **How is sagittal craniosynostosis treated?**

For sagittal craniosynostosis, treatment is best delivered at a specialist centre where a multidisciplinary team approach can be taken. The multidisciplinary team will usually comprise craniofacial (skull and face) surgeons, neuro (brain) surgeons, ophthalmologists (eye specialists), geneticists and speech and language therapists with other specialists brought in as needed.

In many cases, initial skull re-shaping surgery takes place within the first months of life. There are different types of surgery depending on the age of your child at diagnosis – the team will discuss the options with you.

## **What is the outlook for children and young people with sagittal craniosynostosis?**

The outlook for children with sagittal craniosynostosis is good with the vast majority growing up to lead a normal life, working and raising a family. With input from a speech and language therapist any initial delays in speech development usually improve with no lasting effects. Raised intracranial pressure needs to be treated only if it occurs. Children are usually of normal intelligence so do well at school, college and university.