

SINGLE SUTURE NON-SYNDROMIC CRANIOSYNOSTOSIS

MULTI SUTURE OR SYNDROMIC CRANIOSYNOSTOSIS



Discussion with gynaecologist about perinatal care.

If it is **suspected** that your baby has craniosynostosis during pregnancy

You should be referred to a specialist centre for craniosynostosis (cso) for diagnostic tests

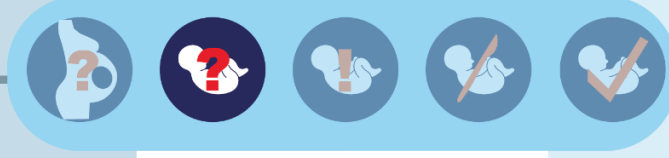
Discussion with gynaecologist about perinatal care.

In the specialist cso centre you should:

- Meet with a clinical geneticist to discuss genetic diagnostics
- Meet with a specialist plastic surgeon/neurosurgeon to discuss possible postnatal treatment options

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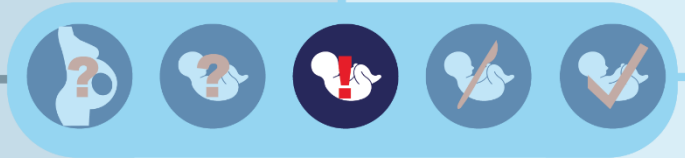
In a specialist cso centre your child should be examined by a specialist plastic surgeon/ neurosurgeon and referred to have diagnostic imaging tests, which may include ultrasound, x-rays and/or a 3D-CT scan of the skull.

If it is **suspected** that your baby has craniosynostosis

You should be referred immediately to a specialist centre for craniosynostosis (cso)

In a specialist cso centre your child should be examined by a specialist plastic surgeon/ neurosurgeon and referred to have diagnostic imaging tests, which may include ultrasound, x-rays and/or a 3D-CT scan of the skull.

For children suspected of having Apert or Crouzon syndrome, this may include a 3D-CTA scan.



If your child has been diagnosed with craniosynostosis

A clinical geneticist in specialist centre for cso should undertake appropriate diagnostic tests

In a specialist centre with expertise of cso:

- Children with metopic and coronal synostosis should be screened annually by an orthoptist and ophthalmologist for any vision/eye problems.
- Children with unilambdoid synostosis should have an MRI scan.
- Your child's ears and hearing should be examined on a regular basis by an ear/nose/throat (ENT) specialist.
- If your child has Chiari (a condition in which brain tissue extends into the spinal canal), you should have the opportunity to discuss possible treatment with a neurosurgeon.

In a specialist centre with expertise of cso:

- Your child should have an MRI scan which will usually be repeated at the age of 4 and again at 18 (or more frequently if there are any problems).
- Your child should be screened by an orthoptist and ophthalmologist for any vision/eye problems.
- Your child should also be screened annually for Obstructive Sleep Apnoea (OSA) until they are 6 years old and receive treatment where necessary.
- Your child's ears and hearing should be examined on a regular basis by an ear/nose/throat (ENT) specialist.
- If your child has Chiari (a condition in which brain tissue extends into the spinal canal), you should have the opportunity to discuss possible treatment with a neurosurgeon.



If your child has a confirmed diagnosis of craniosynostosis and surgical treatment*

In a centre of specialist expertise for cso:

- Your child will be offered treatment according to their age and type of craniosynostosis.
- Children with sagittal synostosis under 6 months will generally be offered minimally invasive surgery, and open skull remodelling after that.
- Children with metopic, coronal or lambdoid synostosis may undergo minimally invasive or open surgery up to the age of 12 months.

In a centre of specialist expertise for cso:

- Children with Apert, Crouzon and multisuture craniosynostosis that involves the lambdoid sutures will usually undergo surgery known as occipital expansion between 6 and 9 months.
- Children with Saethre Chotzen will undergo a procedure known as fronto-orbital advancement between 6 and 9 months; those with Muenke syndrome will generally undergo the same type of surgery between 9 and 12 months.
- Children will also normally undergo specialist treatment with a maxillofacial/plastic or neurosurgeon on their midface between 8 and 12 years and from around the age of 17, although this may be earlier if there are problems for example, with OSA (see above).
- The treatment offered will vary according to your child's facial shape.



If your child has surgically-corrected craniosynostosis

All treatment should be carried out in a centre for craniosynostosis unless the centre has recommended otherwise and co-ordinates the care provision.

In a specialist centre with expertise of CSO:

If your child has sagittal synostosis, an ophthalmologist should check annually up until the age of 6 for any signs of raised intracranial pressure (ICP) by examining the back of the child's eye.

If your child has lambdoid, metopic or coronal synostosis, a specialist plastic surgeon/neurosurgeon should measure your child's skull circumference, and if there are any concerns, check for ICP as above.

Your child should be regularly assessed by a specialist speech therapist at the centre, who should also monitor speech development via school tracking systems and refer your child on for neuropsychological testing where required.

A specialist psychologist should screen your child between 18 months and 4 years for motor development (for example, sitting, walking), cognition (for example, attention, memory, problem solving etc) and behaviour.

Children with metopic, coronal lambdoid synostosis should be screened when they are 8 or 9 years old in primary school for any cognitive or behavioural problems and offered psychological testing where necessary.

Children with sagittal synostosis should be screened in primary school when they are 8 or 9 years old for verbal intelligence, arithmetic skills and behavioural /attention deficit issues and offered psychological testing where necessary.

There should be a social worker to liaise with you/your family and screen for any psychosocial issues you/your child/family may experience.

In a specialist centre with expertise of CSO:

An ophthalmologist should check for raised intracranial pressure (ICP) by examining the back of the child's eye.

For children with multisuture, Apert and Saethre-Chotzen this should be every 6 months until at least 6 years of age.

For children with Crouzon, this should be every 4 months until they are 2 years old, then every 6 months until they are 4, and annually from 4 until at least 6 years of age.

For children with Muenke, it should be annually until the age of 6.

Your child's vision should be fully checked by the ophthalmologist at the age of 7.

A plastic or neurosurgeon should measure your child's head circumference annually.

Your child should be regularly assessed by a specialist speech therapist at the centre, who should also monitor speech development via school tracking systems and refer your child on for neuropsychological testing where required.

Your child should be assessed by an orthodontist before they reach the age of 1 and then again at the ages of 4,6,9,12,15 and 17. A treatment plan, which may include referral to a dental hygienist, should be drawn up when your child is 4 and that treatment supervised by an orthodontist at the centre of expertise.

Your child should be screened by a specialist psychologist at 2-3 years to help determine primary school options, and then again at 7 years of age and when your child is 8 or 9 years old to ensure that any cognitive or behavioural issues are identified and addressed.

The psychology team should regularly assess children using 'quality of life' questionnaires with their parents, and directly with children themselves from the age of 12.

There should be a social worker to liaise with you/your family and screen for any psychosocial issues you/your child/family may experience.

You and your family should be offered support from the centre around your child's transitional phases – for example, when they reach their teenage years. Your child should be offered at least one consultation with a psychosocial social care provider (for example, a specialist counsellor) when they wish to undergo surgical treatment.

