My baby has craniosynostosis:

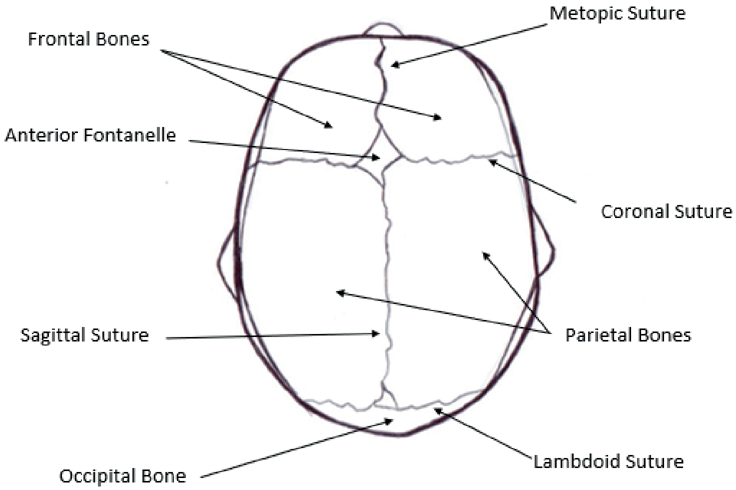
A parent's guide to managing a diagnosis

This booklet was put together by Headlines Craniofacial Support, researchers at the Centre for Appearance Research (University of the West of England), a panel of parents with experience of craniosynostosis, and clinicians from the NHS specialist craniofacial service.

The booklet was designed in response to a national survey of psychological wellbeing in parents carried out in 2019, which highlighted a number of gaps in emotional support for parents following their child's diagnosis. This booklet is a first step toward addressing these concerns.

What is craniosynostosis?

Normal Skull of the Newborn



The skull is made up of several plates of bone which meet at gaps (sutures), called the sagittal, coronal, metopic and lambdoid.

Normally, sutures join (fuse) during adulthood, when brain growth has finished. However, in a small number of babies, one or more of the sutures fuses before birth or early in childhood. This results in a condition called craniosynostosis, where the head is an unusual shape.

We generally talk about two main types of craniosynostosis:

Non-syndromic craniosynostosis usually only involves one suture and does not normally affect other parts of the face or body. There may or may not be an underlying genetic cause.

Syndromic craniosynostosis can affect facial appearance and the appearance of the hands and feet, as well as the skull. A small number of children may also have learning difficulties, hearing impairments, and/or problems with vision. There is often an underlying genetic cause but in many cases there is no obvious family history. Examples of syndromic craniosynostosis include Apert syndrome, Crouzon syndrome, and Pfeiffer syndrome.

It is estimated that craniosynostosis affects between 1 in 1,800 and 1 in 2,000 babies in the UK. Around 75% of these will be non-syndromic, and the other 25% syndromic.

One baby is born with some form of craniosynostosis almost every day in the UK.

How is craniosynostosis treated?

Every child born with craniosynostosis in the UK has the opportunity to be treated at one of five NHS Specialist Craniofacial Units, which provide co-ordinated treatment from a range of health professionals.

The specialist team is often referred to as the MDT (multidisciplinary team) and normally includes surgeons, clinical nurse specialists, clinical psychologists, speech and language therapists, clinical geneticists, orthoptists, and other specialists. The service provides treatment and support for families and individuals from the point of diagnosis through to adulthood.

The five designated Specialist Craniofacial units are:

- Alder Hey Children's Hospital, Liverpool
- Birmingham Children's Hospital, Birmingham
- Great Ormond Street Hospital for Children, London
- John Radcliffe Hospital, Oxford
- Royal Hospital for Children, Glasgow

> **"The specialist team has been amazing, from the initial consultation through to the current day"**
>
> Laura, mother.

Referrals to specialist craniofacial teams are usually made by a General Practitioner (GP), a paediatrician, or another hospital consultant. If you live in Wales or Northern Ireland, you can ask to be referred to one of the units in England.

Your child's treatment pathway will vary according to the type of craniosynostosis they have. Speak to your specialist craniofacial team about your child's individual treatment plan.

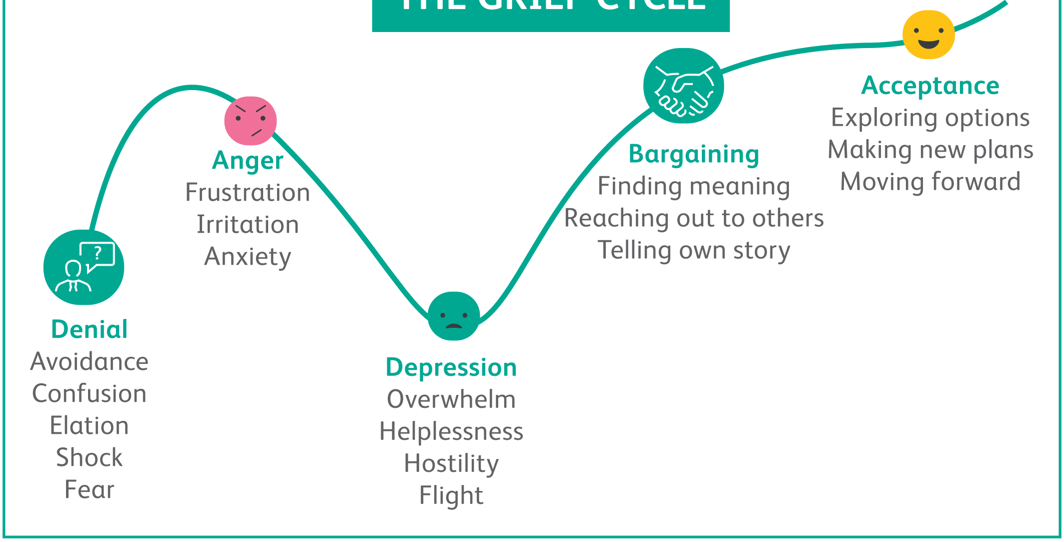
Common concerns

Having a baby is a life-changing experience for all new parents. The birth of a child with craniosynostosis places additional demands on the whole family. Parents may experience a range of conflicting emotions, such as shock, grief, guilt, and anger. All of these emotions are common in new families, and it's OK to feel this way.

Some parents blame themselves for their child's condition. It's important to remember that even if your child's condition is found to be genetic, your child's condition is not your fault.

The "Grief Cycle" was designed by psychologists to illustrate how people cope with a particularly difficult or life-changing experience. Although everyone reacts differently, the Grief Cycle is a helpful tool to understand some of the emotions that parents may be experiencing after a diagnosis of craniosynostosis. Parents often report that these emotions are triggered by different situations, and that they go back and forth between them at different times.

THE GRIEF CYCLE



> **"I felt anxious and depressed. The unknown was so frightening and I blamed myself for it happening"**

Suzanne, mother.

In a recent study, parents of children born with craniosynostosis were asked to identify the key milestones in their journey so far. Although this journey is different for everybody, there are often similarities in families' experiences.

Key milestones during the early years

Pregnancy and birth
Worrying that something may be wrong or different

Diagnosis
Being told your child has craniosynostosis

Accessing treatment
Getting a referral to an appropriate medical team

Treatment decisions
Making decisions about surgery and other treatment

Undergoing surgery
The lead up to surgery and the experience of the surgery itself

Post-surgical experiences
Caring for your child after surgery and preparing for what comes next

The milestones covered by this booklet include:
Pregnancy and birth, diagnosis and accessing specialist treatment.

Pregnancy and birth

For some families, the pregnancy is healthy and the birth is straightforward. However, some families with craniosynostosis report having a more difficult birth. Difficult births can happen for many reasons. One possibility is that craniosynostosis might make it more difficult for the baby to move through the birth canal, because the sutures in the skull are unable to flex.

Experiencing complications during pregnancy and/or birth can be distressing. You may wish to request a post-birth debrief with your midwife. If you continue to feel distressed after the birth of your baby, you can speak to your health visitor or your Clinical Nurse Specialist. There are also local charities who offer support to families following a difficult birth.
For online support, visit **www.birthtraumaassociation.org.uk.**

Some babies with craniosynostosis are born prematurely. Bliss is a UK charity offering support and information to families of premature babies, from birth onwards: **www.bliss.org.uk.**

> **"I had a long and traumatic birth where my baby was stuck… I thought about it for a long time afterwards"**

Geeta, mother.

Diagnosis

Craniosynostosis is classed as a rare condition. Many health professionals may not have seen a baby with craniosynostosis before. The knowledge and understanding that health professionals have about the condition can therefore vary greatly. Some families may find they receive a diagnosis shortly after birth, while for others the process may take longer and be more difficult.

> “I noticed my son’s head and face were different as soon as he was born. [I felt that] all the health professionals dismissed my concerns, and my doctor suggested I was being over-dramatic”

Aleksandra, mother.

If you have not yet had a formal diagnosis, you can seek a second opinion from another GP or paediatrician. You can contact Headlines Craniofacial Support for advice by calling: 07541106816 or emailing: **helpline@headlines.org.uk**. You can also encourage your GP or another health professional to contact Headlines for information.

The quality and quantity of available information about craniosynostosis can also vary. You may find that you receive conflicting advice from different health professionals. Some families choose to do their own research. This can be empowering for families, although online information can also be unreliable or frightening.

For reliable information about craniosynostosis, visit **www.headlines.org.uk** and **www.nhs.uk/conditions/craniosynostosis.**

> “I hadn’t heard of craniosynostosis and didn’t know what the implications would be for my baby’s health and future. A Google search was very unsettling”

Jack, father.

Accessing specialist treatment

Some families find they are referred to a Specialist Craniofacial Unit fairly quickly, while others go through a more challenging process. Again, this may be due to how much the health professionals you come into contact with know about craniosynostosis.

If you are referred to a hospital that is not included in the list above, they are not one of the Specialist Craniofacial Units. The five Specialist Craniofacial Units are funded specifically so that families affected by craniosynostosis can access multidisciplinary care. This is believed to be the most effective approach to treatment. However, you still have a say in where your child is treated.

If you are struggling to get a referral, or think you have been referred to the wrong place, you can seek support from Headlines by calling 07541106816 or emailing **helpline@headlines.org.uk.**

Support for you and your family

Each family has their own story to tell. Whatever your situation, support is available for you and your family. If you are finding this experience difficult, it could be important to seek help. However, not everyone is ready to seek support. Different people also find different types of support helpful at different times.

The main sources of support for families affected by craniosynostosis include:

Clinical Nurse Specialists

Clinical Nurse Specialists are nurses who are highly skilled and experienced in the day to day practicalities of caring for children with particular conditions. Clinical Nurse Specialists may also work closely with local community and other medical services. The primary role of the Clinical Nurse Specialist in the craniofacial team is to support families with a diagnosis, prepare families and young people for surgery, and monitor their progress afterwards. The Clinical Nurse Specialist is normally the first point of contact for new families. You can contact the Clinical Nurse Specialist directly, or through another health professional in the craniofacial team.

Clinical Psychologists

Clinical Psychologists offer support to people of all ages experiencing emotional distress for a wide range of reasons. This can include symptoms of anxiety and/or depression, behavioural difficulties, and family or relationship issues. Clinical Psychologists are an essential part of the craniofacial team. They have specialist knowledge of craniosynostosis and the challenges it can bring. The psychology service can be accessed free of charge as part of the NHS treatment pathway for craniosynostosis.

A Clinical Psychologist will usually be present at your child's MDT clinic appointments. This provides an opportunity to address any concerns you may have around the emotional impact of your child's condition. Your questions may be addressed in clinic, or you could request a separate appointment, either on the same day or at a later point, to discuss any concerns further. You can contact the Clinical Psychologist directly for an appointment, or through another health professional in the craniofacial team.

Headlines Craniofacial Support

Headlines is the leading UK charity dedicated to supporting those with and affected by craniosynostosis and other rare craniofacial conditions. Headlines provides information and support from the early stages of diagnosis, through treatment and beyond. The charity aims to work in partnership with the health professionals providing your treatment plan, and with leading academics to improve care through research.

Headlines offers:

- A telephone helpline (07541106816) and email service (**helpline@headlines.org.uk**): providing free, confidential support throughout your journey
- A peer support service: putting families in touch with each other locally/regionally to share experiences
- A member-only Facebook group, where you can connect with other parents
- Support groups: including one for dads and one for young adults
- Family Weekends: providing families with an opportunity to seek advice and support, meet other families affected by craniosynostosis, and participate in various family activities
- An annual conference: sharing the latest research, medical knowledge and personal experiences
- An e-newsletter and annual magazine: containing regular updates, upcoming events, member stories, informative articles, and fundraising events.

Headlines has more than 2,000 members, made up of families, adults, and health professionals in the UK and overseas. You can become a member of Headlines free of charge at: **www.headlines.org.uk/how_to_join.asp.**

Hannah's Fund

Hannah's Fund is a small UK charity supporting families and individuals affected by craniosynostosis to access emotional support. Visit **www.hannahlindfield.co.uk/hannahsfund for more information.**

Your Health Visitor

Your Health Visitor is often aware of various resources and support services that are available to you locally. Although this support won't be specific to craniosynostosis, you may still find it helpful.

Managing challenges at home

Bonding with your baby

Some parents struggle to bond with their baby straight away. It is common for this process to take a few days, weeks, or several months. Even though your baby has craniosynostosis, they still need the same things from you as any child. Skin-to-skin contact and holding your baby close lets them feel safe. Talking, singing, and smiling at your baby can be helpful. Your baby will already know your voice and will enjoy hearing you talk to them. Dancing while holding your baby close and playing simple games with them can help you to bond. You could also try gentle massage.

> **“We weren’t sure if [my son] would survive… I was scared to love him in case we lost him”**

Matthew, father.

It’s important to remember you are doing the best you can, and to allow yourself time to adjust to your child’s condition. If you still feel detached from your baby after a few weeks and you’re worried it’s interfering with your ability to look after both of you, speak to your health visitor or GP.

Your relationships

Everyone’s relationships can change after the birth of a baby. The birth of a baby with a craniosynostosis can put additional pressure on marital relationships, friendships, and relationships with other family members.

You and your partner

Everyone has unique life experiences that they bring into the parenting role. People also cope differently with the challenges of having a child with craniosynostosis. These changes in your home life may put additional strain on your relationship. You and your partner might disagree about what is best for your child. You may need to support your partner, as well as cope with your own difficult emotions.

> **“The first year especially was really tough on our marriage”**

Mateo, father.

It is really important to communicate with your partner about how you’re feeling, rather than keep your emotions to yourself. Set aside some time to talk about your fears, and listen to one another without judgement. If you are able to speak openly with one another about your child’s condition, this experience may ultimately bring you closer together.

“[My partner and I] didn’t know how to talk to one another about it… Eventually we got counselling which helped”

Nadine, mother.

Research has shown that fathers can feel excluded from maternity and support services. Headlines therefore run a group specifically for dads of children born with craniosynostosis. This provides an opportunity for dads to get together (virtually and in person) to share experiences.

You can talk to a Clinical Psychologist in your craniofacial team for support with any relationship challenges related to your child’s condition. Relate, a UK charity, is the largest provider of relationship support. Visit **www.relate.org.uk** for online support and one-to-one/family counselling. Contact is another UK charity offering support to families with disabled children: **www.contact.org.uk**.

Family and friends

Introducing your new baby to your parents, your other children, and your friends can be difficult. People may not know what to say or how to help. They may also be dealing with their own difficult feelings. Explaining your child’s condition to other people can also be challenging, especially if you don’t have much information yourself. Some parents find it helpful to share a little information with others in advance, to help people over their initial surprise.

Some family members or friends are caring and accepting, and will offer invaluable support to you and your baby. Others might try to help too much, which could feel overwhelming. Sometimes you may not feel like talking about your baby’s condition. People may also be so focused on your baby that they forget to ask about how you are. It’s important to be clear about what you want, so you can get the support you need.

“My parents found it difficult to have a grandchild with medical needs at first, but they are proud of him for how far he’s come”

– Tamsin, mother.

Sadly, some people may pull away altogether. This can be painful, but try to put your energy into family and friends who are supportive.

Siblings

When a baby is born with craniosynostosis, their siblings have to make unexpected adjustments too. They may be jealous of the amount of attention the new baby is getting, or worried about the baby’s health. They may also have lots of questions. You can help reassure them by giving them basic information about craniosynostosis, explaining why their brother or sister is in hospital, and helping them to explain the condition to others.

> “My other children were worried about their baby brother…but they were also wonderful with him and very empathic”

Alyssa, mother.

Having a baby with a different appearance

Managing your feelings

Some (but not all) babies born with craniosynostosis have a different facial appearance, and/or their feet and hands may be affected. Coming to terms with your baby’s appearance can sometimes be difficult, and you may experience conflicting emotions. You may also wonder whether to share photographs of your baby on social media. It’s important to do what feels right for you at that time. It’s up to you who you tell, and how and when you tell them.

Members of the public

When you are out in public, other people may stare, ask questions, or make comments about your child’s condition. Usually, people don’t mean to upset you, but it can be intrusive, especially if it is unexpected. In some cases, it can stop some parents wanting to go out altogether. It can help to have a response prepared in case someone approaches you. If it happens, try to stay calm. There are different ways you can respond. You could tell the person you don’t want to discuss it at all, or you could change the subject. You could give a short description of your child’s condition and then move on to talk about something else. It could help to write some of these responses down and practice them.

> “People on the street would point [my son] out, nudge each other and say inappropriate things. Usually people are just curious, but it can be intimidating”

– Margery, mother.

The way you respond may change depending on the type of question or comment that is made, and how you are feeling that day. It’s important to be kind to yourself in these situations. You may not always respond in the way you would have liked. Try not to let yourself replay the encounter in your head, and instead let it go.

Support for appearance-related concerns

The Clinical Psychologist in your specialist craniofacial team will be familiar with these types of concerns and can offer specific support. Changing Faces is a UK charity offering support to individuals and families affected by a range of appearance-altering conditions. They provide useful guides for coping with your own feelings and for dealing with the reactions of other people: **www.changingfaces.org.uk/parents-families.**

Supporting your own mental health

Often parents are so focused on the experience of having a child with craniosynostosis that they forget to take good care of themselves. Remember that the more you care for yourself, the more you will be able to care for your baby.

Having a baby born with craniosynostosis can bring about experiences that you may find overwhelming at times. There are a range of strategies you can use to help calm you and bring about a sense of stability during difficult times. These include breathing techniques, mindfulness, yoga, grounding statements, and others.

Breathing slowly and deeply calms the nervous system and helps you to feel more in control.

The 4, 7, 8 technique: Breathe in through your nose for a count of 4, hold the breath for a count of 7, and release slowly through your mouth for a count of 8.

Different strategies work for different people. It's about finding what fits for you.
There are a number of apps that can support you with this. These include Headspace (**www.headspace.com**) and Calm (**www.calm.com/breathe**).

These apps may come with a cost, but they usually offer some content for free. You can also visit Mind, a UK charity, for general mental health support. Visit **www.mind.org.uk.**

Examples of grounding statements:

"This is painful for me, but I know I am doing my best"

"This feeling is uncomfortable. It's OK not to like it, and it will pass"

Advice from other parents

A recent study asked parents of children born with craniosynostosis what advice they would offer to families with a recent diagnosis. Their responses included:

Talk things through

Ask for help and information

Trust your instincts

Join support groups

Take one day at a time

Focus on your child's strengths

Take time to enjoy your child

Accept the journey will be difficult, but know there will be many good times too.

Your child’s future

It is understandable if you find yourself worrying about the future. Parents of children with craniosynostosis may need to make decisions about surgery and other treatment. You may also wonder about how your child will get on at school, whether they will make friends, and whether they will experience teasing or bullying.

Try to focus on the present and what you can do to support you and your family at this moment. Remember you can seek specialist support to help you and your child for as long as you need it, whatever your journey brings.

Thank you to everyone who contributed their time and expertise to developing this leaflet. This booklet was funded by the University of the West of England, Bristol, and Headlines Craniofacial Support through a grant from the VTCT Foundation.

Headlines
Craniofacial Support

Centre for
Appearance
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Bristol
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of the
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NHS
Alder Hey Children's
NHS Foundation Trust

NHS
Birmingham Women's
and Children's
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First published 2021