

# Surgery for craniosynostosis:

A parent's guide



# Understanding surgery for craniosynostosis

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. This booklet is the second in a series designed to support parents through their child's early years.

Although this journey is different for everybody, there are often similarities in families' experiences. The milestones covered by this booklet include: Treatment decisions, Undergoing surgery, and Post-surgical 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

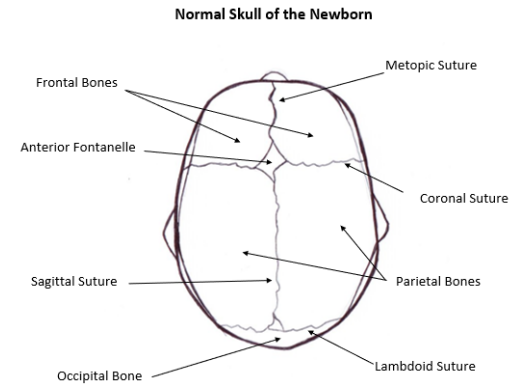
### Undergoing surgery

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 first booklet focused on the experience of diagnosis and can be accessed here: <https://www.headlines.org.uk/for-parents>



## Why might surgery for craniosynostosis be necessary?

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. Surgery may be needed to reshape the skull and/or to make more space for your child's brain to grow.

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

## What surgical options are available?

There are many different types of operations carried out around the world for craniosynostosis. Currently, there is

little scientific evidence to show that one operation is better than another. Because of this, the various craniofacial units may offer slightly different options at different times. Every craniofacial team will carry out the operation they believe is safe and best for your child.

Often, the type and timing of surgery will vary depending on the age at which your child is diagnosed, which sutures are involved and whether your child's craniosynostosis is syndromic or non-syndromic.

If your child is under the age of 6 months, suturectomy-based operations may be available. These involve removing the closed suture and reshaping the head using springs or distraction devices. In some cases, endoscopy (a minimally invasive procedure) may be offered, followed by the use of a helmet, which is worn for at least 12 months after the operation. These surgeries can only be done in young babies when the skull is still soft.

The advantage of suturectomy-based operations is that the incisions are less extensive, which normally leads to a shorter hospital stay, faster recovery and lower blood transfusion rates. The disadvantage is that head growth during infancy is unpredictable, and your child may need more surgery in the future.

If your child is over the age of 6 months, or if you choose to wait to have surgery, vault-remodelling options may be available. These operations involve a long incision to expose the skull more fully, and usually require multiple cuts to the bones to

achieve the desired head shape. Although vault-remodelling surgeries take longer to do, leave a longer scar and have a higher transfusion rate, they can be done at most ages and offer a more predictable and stable result.

### Making a decision about surgery

When it comes to making a decision about surgery, there is no right or wrong choice. We are still learning about the outcomes of different treatments and all treatments come with risks and benefits.



1

#### Understand

Your medical condition and how it will affect your life



2

#### Identify

What decisions need to be made



3

#### List all options

For treating or not treating your condition



4

#### Gather

Details of each option, including benefits and risks



5

#### Decide

On your plan; know that you can re-evaluate or change course

Making a decision about surgery for your child can feel overwhelming and may be time-sensitive. It is important that you seek the information and support you need to make an informed decision, and take time to choose the option that is best for you and your family.

**It took a long time for us to get a diagnosis, so if we wanted surgery before 6 months our decision needed to be quick. We felt pressured, but spent time researching the options ourselves and asking for different opinions before advocating for our final decision.”**

In some instances, you may choose not to operate at all. Opinion is currently divided as to whether operating is necessary in cases where the potential benefits are primarily cosmetic rather than medical. Operating for aesthetic reasons is a valid option, but parents often find this decision to be difficult. Some families choose not to proceed with surgery for a variety of reasons. It is important to think about this and discuss it with your craniofacial team.

**“The cosmetic versus the medical need was discussed, and we did worry that if we made a decision on the basis of improving appearance that this would be for vain or superficial reasons. But we were also aware of the possible emotional impact and other wider implications in the longer-term, and we considered all risks and benefits carefully before making the choice we thought was best on balance.”**

Helmet therapy, in conjunction with endoscopic surgery, may help to improve the shape of a baby’s head as they grow. Helmet therapy is a fairly new treatment and evidence for its use in craniosynostosis is currently limited.

**“We had to go back regularly for the helmet to be adjusted and it was a big commitment. It was hard to keep the wound clean with the helmet on and that was upsetting. People would also stare at us and ask questions when my son was wearing the helmet. So, although endoscopy with helmet therapy requires a smaller surgery, there**

**are other things to consider and weigh up.”**

In addition to discussing surgical options with your craniofacial team, you may wish to seek information and opinions from other sources. This can be empowering for some families, but online information can also be unreliable or frightening. For accurate information about craniosynostosis, visit [www.headlines.org.uk](http://www.headlines.org.uk) and [www.nhs.uk/conditions/craniosynostosis](http://www.nhs.uk/conditions/craniosynostosis)

**“You are always trying to do the right thing without really knowing what the right thing is. The uncertainty is hard, but information is power.”**



# Preparing for surgery

Preparing for your child to undergo surgery can be a stressful experience for you and your family. It is common to feel many conflicting emotions, and important that you take care of yourself during this time. See the 'Support for You and Your Family' section below for sources of support and mental health guidance. It may also be helpful to ask family or friends for practical or emotional support.

## Planning ahead

- **What does pre-operative care involve?**
- **How long can we expect to stay in hospital?**
- **How long will my child's recovery period be?**
- **Can we access free accommodation?**
- **What are our travel options?**
- **What are my leave options at work?**

Pre-operative care will vary depending on the type of surgery your child is scheduled for. Your craniofacial team will be able to tell you what to expect. It may also be helpful to ask your craniofacial team about how long you can expect to stay in the hospital and how long the recovery period could be, so you can plan ahead. Some parents find it helpful to write a list of questions to ask the craniofacial team and/or the hospital staff.

If you live a significant distance from the hospital where the operation will be carried out, you may be able to access free accommodation. You can ask your craniofacial team for advice about this. You can also contact Ronald McDonald, a

charity providing free accommodation to families with a child in hospital: [www.rmhc.org.uk](http://www.rmhc.org.uk). These houses offer en-suite bedrooms, kitchen and communal areas, a place to express and store breastmilk, outside space, and a direct phone line to the hospital. Day passes are also available so you can rest, shower, cook, or spend some time together as a family.

Parking is normally available at the hospital or nearby. Checking your travel options advance may reduce any stress on the day.

If you need to take time off work, it may be helpful to explore your leave options with your employer. Many employers offer some degree of parental leave, or flexible working hours. You may also be able to seek unpaid or personal sickness leave depending on your circumstances.

If your child is ill before the surgery or if something changes at the hospital, the operation may be postponed. This can be a particularly difficult experience for families and it is important to be aware of this possibility.

**“The team tries to prepare you for the surgery date being changed, but the reality is really hard, especially if it happens more than once. The emotional build up and the let-down is exhausting. I would recommend that families be as flexible and as understanding as possible, because there are valid reasons for postponing and everyone is doing their best.”**

## Packing for your hospital stay

The amount of time you and your child spend in the hospital can vary. It may be helpful to be prepared for a variety of lengths of stay.

Hospitals often have many of the things you need, but it may not always be possible to leave the ward. Being prepared may help you to feel more in control.

## Siblings

When a baby is born with craniosynostosis, their siblings have to make unexpected adjustments too. They may be worried about the baby's health, or have lots of questions about why their brother or sister needs to go into hospital. You can help reassure them by giving them basic information about the operation, giving them time to ask questions, and making sure they know what will happen to them while you are away.

**“I explained that her sister had a poorly head, and needed an operation to make it better. I told her the doctors and nurses were very kind and would take good care of her sister. We role-played operations and read a book about going into hospital. Leaving her with her grandparents was heart-wrenching for me, but I told her we would all be together again soon.”**

## WHAT TO PACK

### For your baby:

- Milk/baby food
- Baby clothes that can be put on and taken off without needing to go over your baby's head
- Nappies
- Wet wipes
- A dummy (even if your baby hasn't used one before)
- A blanket or comforter that smells of home/of you
- A familiar toy
- A new toy (consider buying something from the charity shop, doing a toy swap with a friend, or asking a friend/the hospital if you can borrow a toy)

### For you:

- Food and drink
- A refillable drink bottle
- A book, puzzle book, iPad
- Comfortable clothes (layers are best due to the temperature of the wards, and to allow for easy skin to skin contact with your baby)
- Shoes that can be easily taken on and off
- Earplugs or headphones (the wards can be noisy)
- A portable phone charger
- A flannel
- Hairbrush or hair tie
- A hand-held fan (as the wards can be hot)
- Washing tablets for the laundry

## During the surgery

On the day of your child's surgery, you may need to travel to the hospital early in the morning. Alternatively, you may be asked to stay overnight the night before the operation. Once you have arrived at the hospital, there may be a wait while the pre-operative checks are carried out. You may also be asked to (re)sign the consent forms.

**“We were waiting on the ward for the doctors to do the pre-surgical checks. My son had to be nil by mouth, so he was hungry. I was feeling anxious, guilty, distressed. We had to keep him entertained and us distracted, until it was time to go down to theatre.”**

Once you are in theatre, you may be asked to hold your baby while your baby is put under anaesthetic. Once your baby is asleep, you will be asked to leave the room so the surgery can take place. This can be a distressing experience for some parents.

### What to do while your child is in surgery

While your child is in surgery, you may experience a range of conflicting emotions, such as anxiety, sadness, guilt, and grief. All of these emotions are common and it's OK to feel this way.

**“It felt unbearable to walk away and leave my son behind. Nothing could have prepared me for that. But I also knew he would be back with me soon, and that he was in the best hands.”**

You will be told how long your child is expected to be in surgery for. Bear in mind the actual time may be shorter or longer than this. If you are concerned about how long your child's operation is taking, speak to a member of hospital staff.

While your child is in surgery, it could be important to take some time to rest and take care of yourself, as the caring responsibilities after surgery are likely to be high. It can also be helpful to keep yourself busy while your child is in surgery. You may choose to go for a walk, watch a film, or read a book. You may want to visit an outdoor space or a faith room, without leaving the hospital grounds. Ask the hospital staff what facilities are available to you.



## After the surgery

When your child comes out of surgery, there may be some swelling, bruises or blood from the operation. This swelling often reduces quite quickly and rarely affects your baby's vision. You may also be able to see a visible change in your baby's appearance immediately after the surgery.

**“I had no idea what my son would look like after the operation. There were wires taking the excess blood and fluid away from his head and his face was very swollen. It was a bit shocking at first, but he sat up and became mobile quite quickly, and he was still able to see despite the swelling. I was relieved he was OK and actually I was amazed at how much better he looked.”**

**“I knew my baby would look different after surgery and I had wondered whether I would still recognise him and if I would still love him. He did look different, but he was still full of his own character. He was still himself.”**

Initially, your child may be placed on the Intensive Therapy Unit (ITU) or High Dependency Unit (HDU), although this is not always the case. It is important to be aware you may not always be able to sleep on the ward with your child if they are in the ITU or HDU. Ward rounds are often carried out early in the morning. You may like to find out what time hospital rounds take place, so you can be there to speak with the

hospital staff about your child's progress.

Once your child is stable and is placed on a more general ward, you may be able to stay with them. During this time, it may help to be prepared for a lack of sleep, for your child to be uncomfortable or distressed, and/or to experience the distress of other children and families.

**“There was quite a lot of beeping and other hospital sounds, and although my daughter was calm, there were other children on the ward who were distressed, so it was very noisy at times and we didn't get a lot of sleep.”**

It is important to take care of yourself while your child is in hospital. You could also ask a friend or family member to share the caring responsibilities, so you can leave the ward to eat and shower. It may be helpful to ask the hospital staff whether they have any outdoor space or an indoor playroom that you can use once your child starts to feel better, as it can offer a change of scenery and an opportunity to spend time together as a family.



## Being discharged from the hospital

You may experience a range of different emotions once you are discharged from the hospital. All of these reactions and fears are common and it's OK to feel this way.

**“I was so relieved to be out of the hospital and to have this big hurdle out of the way.”**

**“I was really scared to be out in the world again and I wasn't sure how we were going to cope with what would come next.”**

Some parents like to send photos of their child to their family, for example, playing with a favourite toy, before they leave the hospital. This can help other members of the family, including the child's sibling(s), to see that the child is OK and to prepare them

for how the child will look when they come home.

You may also want to plan for the journey home in advance, and ask for support where possible.

**“The journey home was stressful, especially because it was a long journey. I would recommend families think about how long that journey will take, whether you need to build in stops, trying to time the journey so it coincides with your child's nap time, having wet wipes and clean clothes available in the car, and knowing which numbers to call if anything feels wrong. If possible, I would also recommend having two adults to one child in the car so you can support each other.”**

## Post-operative care

Returning home after the operation can feel overwhelming. It may help to have some of the basics covered to help you settle back in at home. For example, you may want to have some freezer meals prepared, or to ask friends or family to cook some meals for you if possible.

**“I'm not someone who reaches out for help very often, but asking people for help around the practical side of looking after ourselves meant we had the energy we needed to look after our baby.”**

### Other people's reactions

Your baby may need to wear bandages for a while and some of the bruises and swelling may still be visible. When you are out in public, other people may stare, ask questions, or make comments about your child. Usually, people don't mean to upset you, but it can be intrusive, especially if it is unexpected. 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 surgery and then move on to talk about something else. It could help to write some of these responses down and practice them.

**“I remember being worried about what other people would think. If I was out and about in a shop, would someone think my child had had a terrible accident and that it was my fault? Having a script prepared in case someone asks you a question can help, because you can't always think on the spot.”**

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 let it go.

### Post-operative recovery

Your child may need to take pain relief for a few days after you return home. You will also need to look after your child's wound, which can be upsetting for some parents.

**“Taking my son's bandages off was quite distressing and his wound became infected. It was quite a lot to take responsibility for.”**

**“We had to turn the distractors in our daughter's head twice a day, which was very difficult and upsetting.”**

In most cases, the scar will have healed within two weeks. You may need to visit the hospital to check how your child's wound is healing and how you are doing as a family.

**“It's so important to take care of your own mental health in all of this and to not feel guilty about that. The more you take care of yourself and ask for help, the more you will be able to care for your baby.”**



# 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 families during the early years. 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, and 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. Clinical Psychologists can offer support to you and your family prior to, during and/or after your child's surgery, at whatever point you feel would be most helpful.

## Headlines

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](mailto: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](http://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](http://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.

## Supporting your own mental health

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](http://www.headspace.com)) and Calm ([www.calm.com/breathe](http://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](http://www.mind.org.uk)

# Your child's future

Examples of grounding statements:

“This feeling is uncomfortable. It’s OK not to like it, and it will pass”

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

## Advice from other parents

A recent study asked parents of children born with craniosynostosis what advice they would offer to other families. 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.

- 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
- Be proud of how far you and your child have come



**It is understandable if you find yourself worrying about the future. Parents of children with craniosynostosis often wonder about how their child will get on at school, if they will make friends, and whether they will experience teasing or bullying.**

These experiences are part of the ups and downs that life brings. One of the most helpful

things you can do as a parent is to work on building your own resilience, and to model positive coping strategies to your children.

Try to focus on the present and what you can do to support you and your family at this moment. Your child will receive care from the craniofacial team as they grow older, and their progress will be reviewed at regular time points to identify any difficulties. Remember you can seek specialist support to help you and your child for as long as you need it, whatever your journey brings.



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