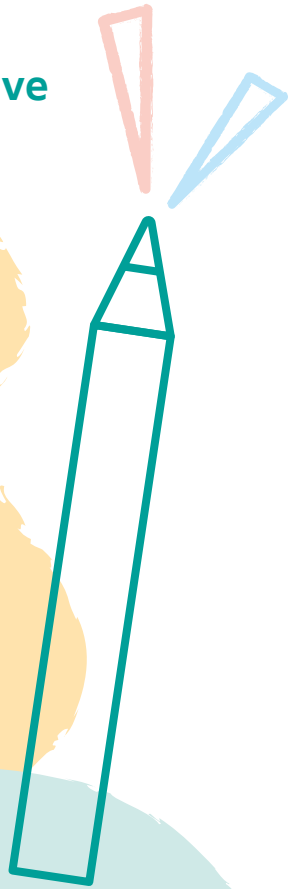
NHS
The Leeds Teaching Hospitals
NHS Trust

Craniofacial Service

Information for young people

leeds children's hospital
caring about children

This leaflet is for children who have "Craniosynostosis"



This leaflet has lots of information in it, but you might still have questions. It can be helpful to write down your questions which you or your parent(s) or carer(s) can ask at your next hospital appointment.

What is Craniosynostosis?

When you are born, the bones in your skull are not joined up together. This is so that your head can grow. Craniosynostosis is when one or more of these bones join together early. This changes how your head grows.

You may or may not have had an operation when you were younger to change the shape of your head. If you did have an operation, you may be able to see the scar across the top of your head.

Not every child with Craniosynostosis needs an operation but we still need to see you to see how your head and your brain are growing.

Different types of Craniosynostosis

Sagittal Synostosis

Coronal Synostosis

Metopic Synostosis

Lambdoid Synostosis

Other related conditions

Why do I need to see so many people?

Everyone has a different role to check how your head and brain are growing. This includes seeing the Craniofacial Consultant or Nurse to measure your head, the Opthalmologist to check your eyes and a Psychologist to check your development.

Tricky words...

"Craniofacial" = This means the bones of the skull and face.

"Consultant" = A hospital Doctor that can offer expert advice.

"Opthalmologist" = A person that checks your eyes to make sure they are healthy.

"Psychologist" = A person that looks at your thinking and behaviour to see how you are developing.

"Development" = This means how your brain is growing as you learn new things.

My appointment with Psychology

The Psychologists in the Psychology Team may have seen you before for something called a "developmental assessment". The aim of this is to find out how you are doing and whether things have changed since the last time they saw you.

What will happen in the appointment?

You will be asked to do some activities with a member of the Psychology Team. These activities might include using blocks and looking at pictures.

Why do I need to do these activities?

These activities have been designed to help the Psychology Team look at your development. This is a way of checking that your brain is growing properly.

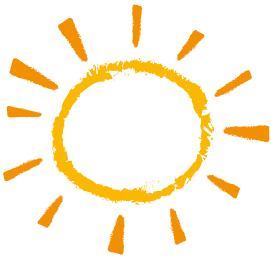
It can feel strange coming into hospital to complete these activities. Your parent(s)/carer(s) will be invited to stay in the room with you.

I am getting bullied because of how I look. What can I do?

Bullying can happen in different ways. It can be **verbal** such as name calling, it can be **physical** such as hitting, it can be **indirect** such as the spreading of nasty stories or it can be done **online** for example by text messages or social media.

Psychology - here to help

Our team of Psychologists can offer sessions to help you learn ways to stop or prevent bullying, manage your emotions and help build your confidence.



If you think that it would be helpful for you to be seen by the Psychology Team to help with issues around your condition, for example, for support with unwanted comments and bullying - speak to your parent(s) or carer(s) who can then contact Leeds Teaching Hospitals Clinical and Health Psychology Department on:

(0113) 392 2284 or **(0113) 206 5897**

It is important to remember that bullying is **NEVER** ok and there **ARE ALWAYS** things that you can do to feel better. Speaking about it is the most important thing that you can do.

Charity Support

Changing Faces

Changing Faces is a UK charity for everyone with a scar, mark or condition on their face or body that makes them look different. Their website has lots of information on how you can build confidence and deal with bullies.

Changes Faces website:
www.changingfaces.org.uk

Headlines

Headlines are a charity that support people with Craniosynostosis. Visit their website to see things that they offer, including a member magazine, a confidential helpline.

Headlines website:
www.headlines.org.uk

YoungMinds

YoungMinds is the UK'sleading charity for children and young people's mental health. Their website has lots of information if you need some support.

YoungMinds wesite:
www.youngminds.org.uk

Useful Apps

GET IT ON Google Play

Download on the App Store

These Apps from the NHS Apps Library can be used to help manage your health and wellbeing. Give them a try and see if they feel right for you. Sometimes it takes a few goes to get used to something so it might help to try them a few times.

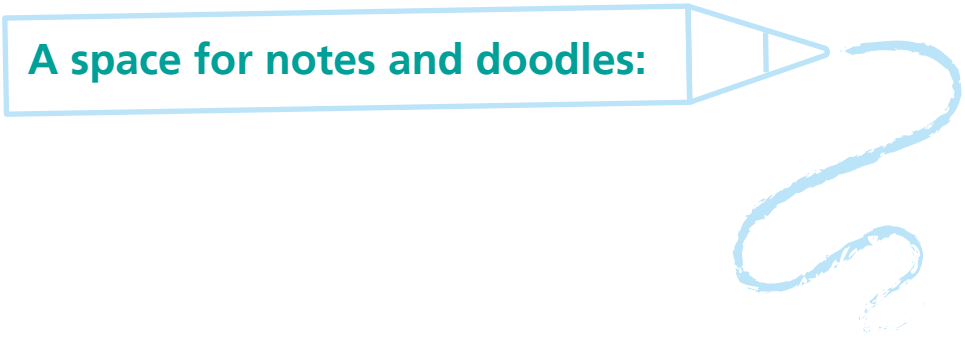
Chill Panda

This App will teach you to relax, manage your worries and improve your wellbeing, using breathing techniques and light exercises to take your mind off your worries.

Cove

This App allows you to create music to reflect your emotions and store them in a personal journal or send them to someone and let your music talk for you.

A space for notes and doodles:



What did you think of your care?

Visit: www.leedsth.nhs.uk/patients/support/feedback-complaints/friends-family-test/

Scan or click the QR code - Your views matter

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