

Craniofacial Service

Information for young adults

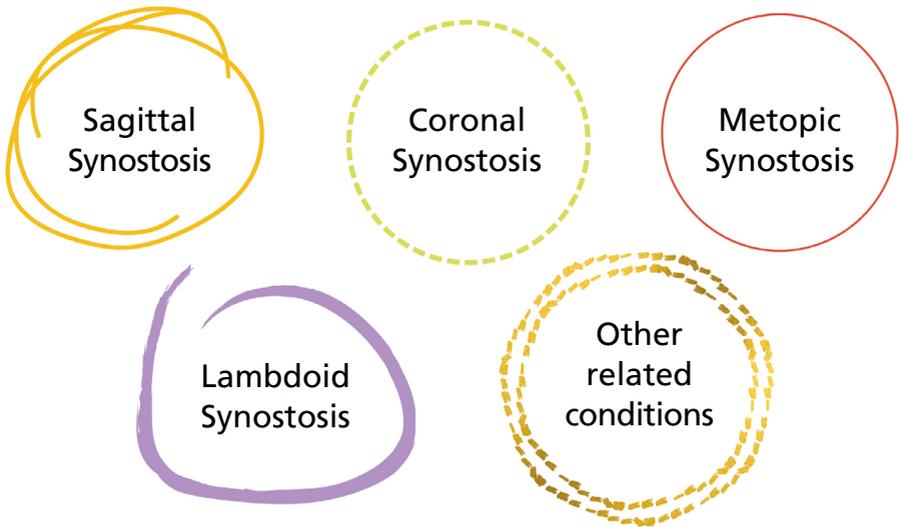


Leeds children's
hospital

caring about children

The information in this leaflet is designed to answer some of the questions that you may have about your **craniofacial condition**. It has been written by members of the Leeds Craniofacial Team, which include Doctors, Craniofacial Nurse Specialists and Psychologists.

Craniofacial conditions



This leaflet includes important information but may not answer all of your questions. If there is anything else that you would like to know, speak to your parent(s) or carer(s) who may be able to help. 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.

Craniosynostosis and me



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.



What does this mean for me?

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 how your head and your brain are growing.



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 Ophthalmologist to check your eyes and a Psychologist to check your development.



My appointment with Psychology

The Psychology team have seen you before for something called a “developmental assessment”. These assessments are a normal part of the cranofacial pathway.

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 working with blocks, answering questions and looking at pictures to recognise patterns.



What if I find it difficult?

Try not to worry. It can feel a little strange completing these assessments sometimes. If you have any questions, you are always able to ask.



Will I need to do any more?

After your 15-year developmental assessment, we would usually not need to see you again, unless requested.



What if I get bullied because my appearance?

If you have been bullied about your head shape or scar, you might have felt **upset, embarrassed, or angry.**



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- If you are being bullied, you should speak to a responsible adult. This may be a family member, school teacher, counsellor or social worker.
 - The important thing to remember is that bullying is not okay and there are things that can be done to stop it.

Psychology - here to help

Sometimes it may not always be easy to talk to an adult about how you are feeling...

This is ok but it is important that you know you can speak to someone else - this is where a Psychologist can help. Psychologists are trained to help people talk about their problems and any difficult emotions or experiences they may be having.

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



All information that you share with us is **treated confidentially** unless there are concerns that you or someone else is at risk.

If you think that Psychology could be helpful for you, speak to your parent(s) or carer(s) who can contact us on:

(0113) 392 2284 or (0113) 206 5897

Where can I find support?

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 is great and has lots of information on how you can build confidence and more.



www.changingfaces.org.uk

Headlines are a charity that support people with craniosynostosis.

Visit their website to see the things that they offer, including a member magazine, a confidential helpline, and invitations to local days out for all ages.



Headlines
Craniofacial Support



www.headlines.org.uk



Hannah's Fund is a charity that offers free psychological therapy by highly trained and qualified psychologists across the UK to individuals with craniosynostosis and/or facial disfigurement.



To apply for this fund and to find out more about why the fund was created, visit their website and complete the application form.

www.hannahsfund.co.uk

YoungMinds is the UK's leading charity for children and young people's mental health. Visit their website to find out about the support that they can offer.

in support of
YOUNGMiNDS



www.youngminds.co.uk

Useful Apps

The following apps from the NHS Apps Library can be used to help manage your health and wellbeing.



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.



Catch It

This App helps you to look at your problems in a different way to improve your mental wellbeing.



eQuoo

An evidence-based and captivating choose-your-own adventure game that increases your emotional fitness and teaches you new psychological skills, helping you to level up in real life.



MeeTwo

A safe and secure forum for any teenagers to discuss any issue that affects them. You can also access anonymous advice from experts.



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A space for notes:





What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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