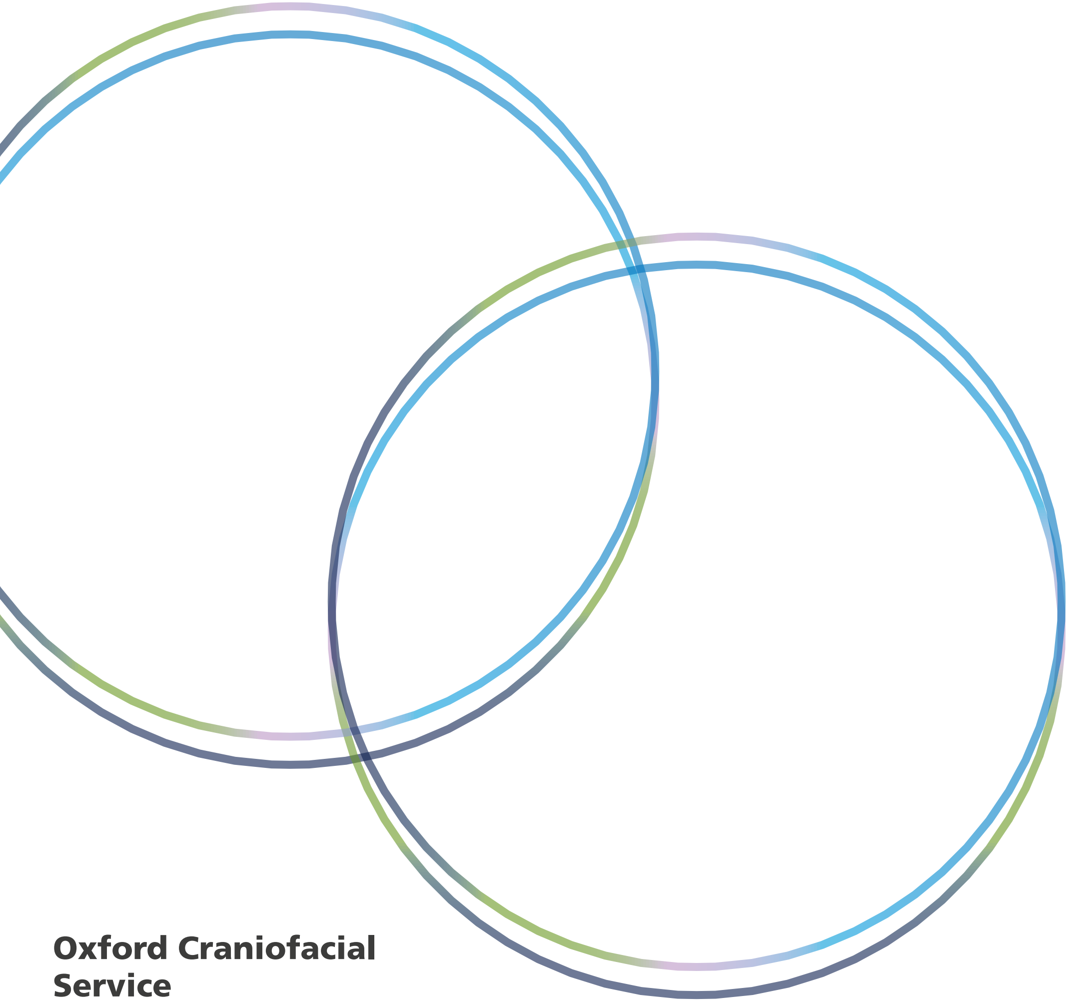
Oxford University Hospitals
NHS Foundation Trust

Managing the reactions from others

Information for patients and carers



Oxford Craniofacial Service

Some children and adults may not have met someone with a craniofacial condition before and this can make them look a little bit longer than normal or want to ask questions.

They may not think the difference is bad (it is just different), but they may be curious about your experiences.

At times this can make us feel uncomfortable or unsure as to how to respond. It is helpful to have things you can say or do if asked about your scar or speech.

Here are some things you could try...

Use your body

- Smile and make eye contact
- Act confidently to help yourself feel confident
- Walk tall with a good posture.
- You can walk away if you want to!

Use your voice

You can share **as much or as little as you like**, and this might be different for different people or situations.

We recommend giving your responses **a practise** with family and friends first so you feel really confident with it! Having a well-rehearsed answer up your sleeve helps to demonstrate your confidence.

Use a calm and confident tone...
“I’m absolutely fine thank you”

Set boundaries...
“I’d rather not talk about it actually”

Explain, reassure, distract

1. Simply explain

- Be polite and positive...
  “Thank you for asking me”
- Be factual...
  “I was born with my craniofacial condition. That means...”
- Acknowledge difficulties...
  “It can affect the way I speak, but people soon understand me”

2. Reassure others

- **“The doctors treated me when I was little, I am fine now”**
- **“It doesn’t affect me in any other way”**
- **“It’s just the way my face is, don’t let it bother you”**
- Tell others you are okay with yourself and proud of how you look

3. Change the subject

- You could ask them a question...
  “Do you have anything different about you?”
- Change the conversation to...
  - The weather
  - Hobbies
  - A new subject
  - Homework
  - Let’s play!

Use your thoughts

It can be helpful to…

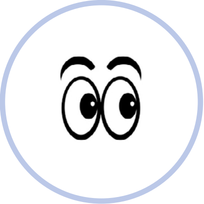
- Notice the difference between a rude reaction and curiosity
- Remember they may be noticing **other things** about you, for example:
  - They're admiring my lovely hair
  - Perhaps I look like someone they know
  - Maybe they like my outfit
  - They know someone else with craniosynostosis
- We can use our thoughts to reassure ourselves:
  - **"It is not my problem it is theirs"**
  - **"Staring is rude and I don't need to talk to someone who is being rude"**
  - **"I am more than how I look"**

Do you have a motto?

Sometimes having a motto or phrase you can say when things feel tough can be really helpful!

- **"I am strong, look what I have got through"**
- **"I can do this"**
- **"I am more than my cranio condition"**

Responding to staring



Some people may not realise they are staring, or that it makes you feel uncomfortable.

You could try the following...

- Look at them, smile or nod
- Look at them, raise your eyebrows
- You can choose to ignore them, turn your body or walk away
- Or if you want you can say something...
  - **"Are you looking at my scar, do you want to know more about it?"**
  - **"Are you looking at my facial features/head shape, do you want to know more?**

How can parents help?

- Children look to adults when learning how to behave and respond. Practise **how you** respond to comments and staring... you can use the tips above!
- **Talking about visible differences openly and in a relaxed and confident** way can help your child feel accepted and that it is not something to be ashamed of.
- Being open with your child about your family's experiences with a craniofacial condition. This **gives your child permission to talk** with you about their own experiences.
- Before going to new situations, like new clubs or schools, **give your child time to practise and prepare** their own responses with you in a safe place. You can use role play or model your own answers to help.
- If you are asked a direct question by others **empower your child** to answer for themselves or join in the conversation if they wish.
- Notice when your child responds to questions and **praise** them for giving it a go!

- You might want to pass on these tips to teachers or other adults who can support your child as they are learning these new skills.

Am I being bullied?

Lots of young people worry about getting bullied or teased and this can feel even bigger if you feel there is something different about yourself that other people might notice.

Having a craniofacial condition does not mean you will experience bullying. However experiencing unkind comments or teasing is **not okay** and is not your fault.

What is bullying?

Bullying is when a person or group of people repeatedly do things to upset, hurt or humiliate you.

It can take different forms:

- **Through words**: Name calling, spreading rumours, threatening you, talking behind your back.
- **Through actions**: Leaving you out, making faces, hurting you physically.
- **Bullying online or over the phone**: Posting nasty messages or pictures, hacking your social media accounts, making silent calls.

How to manage bullying

Bullying can be very upsetting and scary. Remember it is not your fault. It is the person or people doing the bullying that need to change, not you.

Get help: It can be really hard reaching out to the grown ups around you when talking about bullying. People are often embarrassed or worried it will make it worse. However it is a big and brave first step to helping the behaviour stop and you do not have to deal with this on your own.

Who to talk to? It can be any adult you feel you can trust! If it is too hard to talk face to face consider writing it down, or getting the help of a friend to support you. If you are getting bullied at school, it is the school's responsibility to support you and stop the behaviour.

Keep a record of what happened to you over the times you were bullied (this includes any online bullying). This can include **when**, **where**, **who** and **what happened**. This will help others know how to help you.

Know your friends: Make sure you spend time with people who make you feel good!

Practice your response: People who bully others are often looking for a reaction from you, you can take the power out of the situation by remaining calm and not giving a reaction. If safe to do so you can hold your posture high, make eye contact and say a clear, firm 'No'. Or you can choose to ignore them and walk away.

Seek out a place of safety: If you are at risk of harm walk away.

Manage your online accounts: Consider the privacy settings on your online accounts, do not share your passwords with anyone and block anyone who may be involved in targeting you. You can set your platforms so that you can only add people you approve of. You may decide to come off some platforms if they are contributing to the bullying experiences.

Be kind to yourself: Being bullied can leave you feeling sad and can take its toll on us. Remember how amazing you are and all the wonderful strengths you bring. Make sure you do activities that you love and that will boost your mood. That might mean playing your favourite computer game, spending time with family or listening to your favourite music.

Now that you know some helpful tips, try and come up with some examples that work for you.

Write them in the spaces provided below...

Your examples

1. Simply explain: What is your cranio journey?

2. Reassure others:

3. Change the subject: What things interest you?

My motto is:

My helpful thoughts are: What can I say to myself when people ask me questions or stare...

How can we help

The psychology team

If you are struggling to develop a comfortable narrative around your condition, the Craniofacial Psychology Team can support you.

How psychology can help

- Talk through worries and concerns.
- Confidence building techniques.
- Developing self-esteem.
- Creating a cranio condition narrative.
- Help manage difficult feelings.

Contact information

Oxford

Email: ccfp@ouh.nhs.uk

Telephone: **01865 226 966**
01865 234 264
01865 234 714

Or you alternatively you can reach out to any member of the craniofacial team in clinic for a referral.

Useful books and resources

Headlines Charity

A useful charity packed with advice and guidance on living with craniofacial conditions.

Website: www.headlines.org.uk

Hannah's Fund

Read about Hannah's story - living with Pfieffer syndrome.

Website: www.hannahsfund.co.uk

Kidscape.org.uk

A website to support young people and families with experiences of bullying.

Website: www.kidscape.org.uk

Changing Faces

Website: www.changingfaces.org.uk

A charity for those living with visible differences.

References

- **Changing Faces**
- **Kidscape.org**

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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www.ouh.nhs.uk/information

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