Talking to your child about their cleft

Who is the leaflet for? What is its aim?
This leaflet is aimed at parents or relatives of children born with a cleft. The aim is to give parents or relatives information and suggestions to help them talk to the child about their cleft.

Why should you talk to your child about their cleft?
If your child understands about their cleft, he/she will be much better equipped and confident to deal with questions from others and explain all about their cleft when the time comes.
You might worry that talking to your child about a difference he/she has not yet noticed will make things worse. But in fact the opposite is true. Having a basic understanding about their cleft and a simple explanation to give others can help children to feel less anxious that there is something wrong with them.

If a child is unsure why they have been to hospital so much or why they have a scar on their lip or difficulties with their speech, it can lead to confusion. This in turn may make it harder for them to deal with questions and comments as they get older.

You can support them to develop their personal story by integrating cleft facts and discussion in everyday life as early as you can.
Your child is naturally curious about the world and will welcome simple clear facts. Your own openness will prepare your child to feel confident to talk about their cleft when the situation calls for.

**How should I talk to my child about their cleft?**
Below are some suggestions to help you, and remember - your child’s cleft is part of who they are, part of their identity.

- You may find it helpful to begin to build up a bank of photos and information in preparation for telling your child all about their cleft. Many families have found it useful to take photos in hospital so they can show their child later on. Some parents have put these photos together to make a book about their child’s journey and some children have found it fun to make their own and share it with nursery or school for example.

- It is important to remember to give your child this information alongside other memorable facts about them as a baby, for example, what was their favourite toy, a funny family story or how brave they were. This will reinforce all the other important, loveable things about them.

- When looking back at photos from the early days, discuss the changes and events that happened. For example, here you are when you were born – see how you had a gap in your lip? And this is you after the operation at the hospital to close the gap. Can you see your scar? I also have a scar on my leg/chin/arm, etc…
• These are some examples from parents:
  o I just tell the kids who ask to feel the little lines above their lip. I tell them that our lines joined together before we were born but my baby's did not join. I tell them the gap does not hurt and the doctor is going to close it.
  o Having a family photograph album with pictures of her before and after her operation made it really easy to talk about her cleft lip as just one more event in her life, just like her first day of school.

Your child’s cleft is part of who they are, part of their identity.

These are some of the words/ sentences you might find helpful to use

• Your lip/palate didn’t close properly when you were growing inside mummy’s tummy.
• You looked different when you were born / special smile.
• You were born with a little gap/split under your nose and/or inside your mouth/ it did not hurt.
• You had special bottles to help you drink.
• You had an operation(s) to help your eating and talking when you grow up.

If you find talking a bit difficult, don’t forget you can also use the support of children’s books about difference or going to hospital, children’s TV programmes or playing with hospital toy sets. Role play staying in hospital with your child’s own toys/dolls can also be helpful.
Contact details
Cleft.NET.East (Cleft Lip and Palate Team) -
East of England Cleft Network, Box 46, Addenbrooke's Hospital,
Hills Road, Cambridge, CB2 0QQ
Cleft Office Tel: 01223 596272

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site.
For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:
If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history
Authors Cleft psychology team
Pharmacist N/A
Department Cambridge University Hospitals NHS Foundation Trust,
Hills Road, Cambridge, CB2 0QQ www.cuh.org.uk
Contact number 01223 596272
Publish/Review date May 2018/May 2021 (minor amendment made March 2020)
File name Talking_to_your_child_about_their_cleft.doc
Version number/Ref 2/100809

Talking to your child about their cleft

Innovation and excellence in health and care
Addenbrooke’s Hospital I Rosie Hospital