

3 – 6 years. Guides for Parents

Guide 1. Talking to young children about disfigurement

Often parents say, "I'm not sure whether I should talk to my child about his appearance. It doesn't seem to bother him." A child's disfigurement may not bother him or he may not have noticed that he looks different to others but talking openly and honestly about disfigurement, special needs, disability or a medical condition will help your child to feel accepted and valued as a person, as well as building his self-confidence and self-esteem.

Talking about looking different can be a difficult or worrying prospect for a parent. The ideas and suggestions contained in this guide can help you develop ways of talking not only to your child but also to siblings, friends and other children with whom you may want to talk about your child's condition.

1 WHY TALK ABOUT LOOKING DIFFERENT WITH YOUR CHILD?

Children naturally become aware of difference

Children naturally become aware of, and curious about, difference whether or not they have a visible difference themselves. Toddlers start to talk about being "big" or "small"; they can discern one colour from the other; they learn that boys and girls are different.

You are probably familiar with the many 'Why?' questions that toddlers ask like, "Why does that man have long hair?" or "What is that on that man's face?" (pointing at a moustache). In the same way, a child with a visible difference may be asked, "What's wrong with your hands?" Equally, your child may turn to you and ask, "How come my face looks different to my sister's?"

These kinds of questions can be quite surprising and they are sometimes not easy to answer. Children's questions don't always come out in a polite or expected manner. Remember, their curiosity and questioning helps them understand themselves and the world they live in. If you can find the words to talk about your child's disfigurement, you can prepare him to handle people's natural curiosity about difference with confidence.

Building a positive self-image

Talking about your child's disfigurement with confidence and in a matter-of-fact way instils the belief that it is OK. He is likely, at some point in his life to encounter reactions of curiosity, surprise or even dislike from others. A positive image of self, that includes not only his disfigurement but also an acknowledgement of his talents, positive personality traits and likes and dislikes, will help your child to cope with life's inevitable ups and downs.

As a result, negative remarks about appearance that do not fit with his view of himself will be discarded in favour of the storehouse of positive images and beliefs he has built up.

Allaying a child's fears or concerns about his disfigurement

Children will naturally pick up information about their disfigurement from what they hear and see around them. A child with a medical condition goes to extra doctors appointments, sees consultants and other professionals (e.g. speech therapist, psychologist, physiotherapist). You may be administering medicines for their condition (e.g. creams for eczema or birthmarks) and giving explanations to other people in front of your child.

Children think in a different way to adults and if their disfigurement is not spoken about directly, a child may begin to wonder why. Children often have fears and worries about their condition and can end up feeling very alone, scared to talk about it or think that they have an unusual appearance because they did something wrong.

Talking to your child about his condition can allay these fears before they arise and will help your child to feel more confident and secure. It also allows your child to feel that he can turn to you whenever he wants to share his thoughts, feelings and fears.

Preparation for curiosity and questions from others

You may already be aware of how people respond to your child's appearance. They may stare or ask you questions about your child; they may even be rude. Other people's reactions can be very difficult to respond to, yet building up strategies and responses is the best way to build up your own and your child's confidence.

As your child grows he will also find it helpful to learn how to manage other people's reactions himself and the best support you can give him is the tools to handle these. This starts through modelling how to respond to situations, acknowledging feelings, admitting when you have got it wrong and being there to listen to and support your child. By observing how you respond to the reactions of others, your child will learn not only to give simple explanations but also understand that his difference is not something to shy away from or be ashamed about.

2 IDEAS AND SUGGESTIONS FOR TALKING TO YOUR CHILD

Use honest, simple, age appropriate explanations

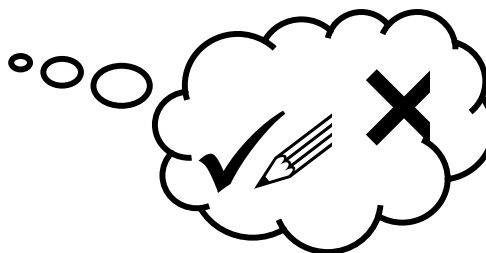
The key to explaining things to young children is to keep it simple, be open and honest and use language that your child can understand remembering that your child's difference is one part of who they are. At first having a whole sentence or explanation may be hard or feel uncomfortable. You could try by just giving it a name.

- "It's a birthmark."
- "This is your small ear."

Use words that describe colour, shape, texture

It is helpful to use words that describe what a disfigurement looks like. Think about the colour, shape and texture of your child's skin, scar or noticeable feature. Take a look at the words on the next page to see if you could use any of these. Are there any you dislike? The word you dislike may be one that your child or someone else likes. Choose what feels comfortable for you and build a sentence around it.

LIST OF WORDS



disfigured	bulgy	
different	special	
lumpy	uneven	swollen
funny	raised	stick out
smooth	birthmark	small
odd	hairy	flat
thin	brown	blue
long	pink	pale
droopy	crooked	accident
unique	scar	burns
brown	sunken	operation
asymmetrical	noticeable	bumpy
flaky	red	

- “You were born with Moebius. I can’t see you smile but I can hear it in your excited giggles.”
- “This is your cleft. The doctors will fix it soon.”
- “Your skin is red and bumpy. It is a scar from where the hot water fell on you.”
- “Your head is bigger than most people’s. It is the way you were born.”
- “You have eyes that bulge out. Mummy has eyes like that too. Daddy doesn’t.”
- “This is your small ear, this is your big ear.”
- “I am putting cream on your dry/itchy skin.”

Sometimes it is possible to compare a particular condition to something else familiar so that it seems less scary or unusual.

- A strawberry mark (name for a small red birthmark)
- It is like a mole, only bigger (for a CMN or hairy naevus)

Discuss some words with your partner or someone supportive and try to come up with explanations that you are comfortable using. Once you have found the explanations that you like, it helps to practise them first before you start using them with your child.

Use the medical name

Your child will overhear medical names in conversations and at appointments and it is important that you introduce your child to the medical name for his condition (if there is one). At first he may not understand the details of his condition but he will become familiar with its name and will not think that it is a topic to be avoided.

Explaining syndromes or a rare condition isn't always easy. You can use the medical name in conjunction with simple explanations about what a disfigurement looks like and how it affects a child. You could say: "You were born with a head that is a different shape and with your fingers stuck together. The doctors call this Aperts."

Many children with long term medical conditions develop a medical knowledge beyond their years and can, as they get older, explain complex medical things. This is because they feel comfortable with the terminology and are confident in speaking about it.

Using names like "special mark"

Many parents come up with positive names for their child's condition like, "your special mark" or "your special ear" which help a child feel confident and positive about their difference but children may have operations later to change their appearance (removal of a birthmark, corrective surgery, or the reconstruction of an ear). They will then wonder why their visible difference, which was so special has to be changed. Try to use names and explanations that describe the disfigurement and provide children with simple explanations for treatment (e.g. it will become less hairy, it will make it smoother.)

How you say it is important

With young children it is not only what we say but how we say it that is important. Young children learn a lot from listening and from our body language and our tone of voice. Portraying calmness and comfortableness, when touching your child's disfigurement, when looking at it or when talking about it, can provide a child with the sense that it's OK. If you can talk about his visible difference in a confident, matter of fact way, your child will have a positive example to follow as he grows up.

Taking opportunities to talk

On a daily basis you will be comforting, bathing and playing with your child. When brushing his hair you may comment on the colour of his eyes. When in the bath you may name fingers, toes and ears as you wash them. Try to name any different features too (e.g. this is your small ear, this is your strawberry mark). He will notice if you avoid talking about it!

With young children there is no need to sit down and have a long discussion. Small explanations and descriptions can be used in daily activities. A young child's curiosity about various subjects can provide many unexpected opportunities to expand on explanations: while you are in the car waiting to pick up an older sibling, questions about baby photos, an aside to another conversation.

EXAMPLE

Ben, aged 4, asks his Mum about one of his baby pictures. He is very interested so she tells him that he was born early in the morning, in a hospital and that Dad was there too.

She gave simple explanations about his condition and the difficulties he had at birth by saying, "You were born with Crouzon's. This means that your head is a different shape to mine or Daddy's. This made it difficult for you to breathe. The doctors had to use a special machine to help you breathe. If you look at this photo, you can see the machine."

You might be anxious about talking about when your child was a baby or his birth, particularly if this was a stressful time but if you can be calm and explain it gently, your child is likely to find it interesting and helpful. What is strange for a young child is not knowing and wondering why they are different.

Some parents put together a short story about their child's life giving simple explanations about the condition, appearance, any operations and other important events (e.g. birth of a sibling, birthday party, special holiday). It is helpful to include current information about your child describing what he likes doing, what he is good at and some of his favourite things or places.

Talking to your child about when he was born can bring up difficult memories for parents. If you are finding it difficult to talk or are feeling anxious about it, you might find it helpful to talk to someone. See the *Changing Faces* Guide on *Finding Further Support* for more information.

3 MY CHILD HAS COMMUNICATION DIFFICULTIES

Some children learn to talk later, have hearing difficulties or are visually impaired. This will impact on how parents communicate with them. If you are in this situation you may be unsure about what to say to your child about his disfigurement.

- Try talking to him even if you are unsure if he can hear, see or understand you. Even if your child does not fully understand the words you are using he will learn that you are comfortable with his disfigurement.
- Make sure you have his attention and that he is calm. Eye contact is essential for children with hearing difficulties or concentration difficulties.
- If your child has a visual impairment you can help him to feel the disfigurement (e.g. lumpy skin from burns or a small eye) so that he can begin to learn new words and understand more about himself.
- If you are learning or using a specific communication method (BSL or Makatan), ask your teacher to help find ways to describe your child's disfigurement.

4 TALKING TO SIBLINGS

It is natural for siblings to be curious or concerned about their brother or sister's disfigurement. Older siblings will be aware of stares or comments made by adults in public and may be asked questions by other children (friends or classmates) or even teased.

It is important that siblings are given simple explanations about their brother or sister's visible difference from early on. This will help them to understand and accept their sibling the way they are and feel confident in responding to questions or comments from others.

5 TALKING TO OTHER CHILDREN

Young children may comment or ask about a child's visible difference. They may point, try to touch or pinch birthmarks or shy away from a child with a skin condition. They may not intend to be rude but what they say can come out bluntly or in exclamations of shock, surprise or dislike.

If you can give simple explanations to young children, you will satisfy their curiosity, provide them with information that alleviates any uncertainty and promote the idea that your child's disfigurement is just one part of who they are.

6 EXPANDING ON EXPLANATIONS AS CHILD GETS OLDER

Answering your child's questions

As your child grows older he may want to know more and you may need to sit down for short periods of time to talk about it. Choose a time when your child is in a receptive mood. Make sure you have his full attention. If you can, prepare yourself for what you would like to say and think about what he might want to ask. You may be surprised by the questions a child asks you.

EXAMPLE

Bill, aged 3, turned to his Dad and said, "I have one small ear." In the past his parents had always said, "It's the way you were born." Bill had made this statement repeatedly over the last few weeks and they realised he was trying to ask more about it.

Dad gave some further information: "The doctors call it Microtia. It means that this ear is smaller than the other. You cannot hear with your small ear. I stand by your big ear when I speak to you so that you will hear me."

Dad left it at that but had prepared more in case Bill was interested. This is what he might say if Bill seems keen or when Bill is a little older: "When you are older you can, if you want, have a new ear built for you by the doctors. If you want to know more about it all you have to do is ask me or the doctor."

Describe how your child's disfigurement does (or doesn't) affect him

As children grow older their curiosity and understanding increases. Expand your explanations to provide further information about treatment, medication, and how a condition affects their abilities. If your child's condition does not affect his abilities make this clear too.

EXAMPLES

- "You wear glasses because your eyes need help to see."
- "This is your micky button. We feed you through this."
- "This is your trach to help you breathe. The doctors put it in when you were born."
- "Your hand can't grip things. This means you have to do most things with one hand."
- "You were born with a head that is a different shape to other children. That is all that

is different. You enjoy playing and having fun just like any other child.”

- “Your dry, red skin is called eczema. To stop it from itching all the time I put cream on it every day. Would you like to help?”

Talk about similarities and strengths

The tips so far have focused on explaining your child’s medical condition. There is so much more to your child that makes him unique and loveable as well as similar to others. It is important to mention that they might look different but that they also have lots in common with other children. Be specific and name these commonalities (e.g. likes football, hates maths, can read and write, loves playing at break time)

Take time to praise and comment on things you like about your child and to compliment him when he does something well. Children thrive on this as it helps them build a sense of who they are, what they can do and to feel good about themselves. If a child hears positive things about his appearance, visible difference, personality and abilities, he will develop a well-rounded self-image and positive self-esteem. No matter what others say he will know that he is worthwhile.

7 TALKING ABOUT FEELINGS

A Parent’s Feelings

Many parents feel angry, guilty, sad or exhausted from having to deal with other people’s responses.

There may be times when you want to protect your child by keeping your emotions to yourself, especially if someone makes an unkind comment in the course of your daily activities. However, children will often pick up on anxiety or annoyance from your body language or facial expressions as they are alert and aware even if they are unable to clearly articulate this.

In these situations it helps to acknowledge your feelings and model how to deal with the situation with your child. For example, if someone’s reaction makes you feel upset, you could say to your child:

- “I feel angry when people make unkind comments about your eyes. I would prefer they asked nicely or left us alone.”
- “When I feel like this, I like to have a chat with a friend. If you want to chat about it, or if you just want a hug, let me know.”

Your child will know that it is safe to share his feelings with you and that he will be listened to with interest, caring and understanding.

Your Child’s Feelings

You may want to protect your child by avoiding situations that could make your child feel upset or angry (e.g. going to public places where people may stare or comment) or by not mentioning difficult feelings.

No matter how much you may want to protect your child from people's reactions to his disfigurement, he will encounter them at some point. Experiencing a variety of feelings including anger, sadness and irritation (and many more) is part of life and children need to learn how to name these feelings, talk about them, respond to them and express them appropriately.

You can start by naming feelings in your child and yourself:

“You are so happy today.”

Then, link this feeling to your child's behaviour, body language and facial expressions so that he learns how to identify and express emotion:

“You have such a big smile, your eyes are shining, you are giggling, I can see your legs kicking for joy.”

If your child has restricted facial expressions, he may not be able to smile or show emotions easily. You can still continue to encourage him to express and identify his feelings.

“You look happy. Your face just lit up. I noticed your arms waving with excitement. Are you happy to see Granny?”

“You seem really mad. You are stamping your feet and shouting. I know you don't want to do what Mummy says.”

Knowing how we feel and being able to express this is important for everyone but it has added significance if a child has limited facial expression because other people may struggle to identify his feelings or may misread them. If a child is comfortable expressing his feelings and labelling them for others, he can help those he meets to understand and learn how to read his emotions too.

Helping your child to express his feelings about his appearance

It is important to give your child the opportunity to express how he feels about his appearance. If you hear him say, “I hate my nose.”, let him know this is OK as we all have parts of us we do not like. He may well realise that this cannot be changed but it will be a relief to be able to share this with someone he trusts and is open to listening.

Ask him what it is he doesn't like about his nose (or ear, or scar or lip) rather than why questions as he may not know how to answer these. He may have heard somebody say something about his disfigurement or there may be a very practical reason, e.g. it is hard to breathe through my nose, people always comment about my scar for not liking it.

Being able to say, “I don't like my nose.... my burn scars.... my wobbly face.” allows a child to be specific about what he doesn't like rather than it being unsaid and developing into “I hate myself because I look different”. Also, being able to talk about feelings and clarify exactly what it is that is frustrating will give your child the space to focus on the things he likes about himself so be sure that you mention these things too.

The more words children learn to express their feelings, the less likely they are to show them through behaviour or bodily feelings (e.g. hitting, bullying or having aches and

pains). If you are unsure what is appropriate or you are struggling with your child's behaviour or feelings about himself, look at the *Changing Faces Guide on Finding Further Support*.

9 WHAT IF I DON'T GET IT RIGHT?

There are lots of ideas in this guide so take things step by step...

To start with, try thinking about how you talk about your child's condition to others. Do you ever explain it to other people? Have you done this in front of your child when he was a baby or a toddler? How do you explain their visits to doctors? If you have an explanation for any of these questions then you are already talking, in small ways, to your child about his visible difference.

If you already talk with your child and feel you didn't answer the way you would have liked, it's OK to go back and try again. You are teaching your child valuable skills and the important thing is to keep trying and keep it simple.

Go back to the ideas you wrote down and remind yourself of what you want to say. Your child may not have much to say at this time or may not look that interested in what you are saying. This is OK. You are keeping the lines of communication open. Remember to let him know that he can ask questions or talk with you again if he wishes.

10 I'M FINDING IT DIFFICULT TO TALK

You may have read this Guide and thought, "The ideas make sense but I just can't do it" or "I've never talked to my child about his appearance and I don't know where to start."

As the parent of a child with a visible difference, there are so many things that can feel strange and overwhelming. At this point in time, you may have other priorities - your child may just have been diagnosed or may still be receiving treatment – or everything might just feel very busy. If this is the case why don't you put this Guide down and return to it when it suits you? Focus on what is important right now, give yourself some space and time, and make sure you take care of yourself.

Many parents find it helpful and reassuring to talk to someone who understands the unique situation they are in. It can be liberating to be able to express your feelings openly either on your own or with a partner about having a child who has a visible difference.

You can contact *Changing Faces* on 0845 4500 275 or email info@changingfaces.org.uk for professional support, information and advice. *Changing Faces* can also put you in touch with other organisations and support services which might be useful at this time.