

7-11 years. Guides for Parents

## **Guide 1. Talking to older children about disfigurement**

A child with a visible difference may be asked: "What's wrong with your hands?" or "What is that on your face?" Your child may also turn to you unexpectedly and say, "How come my face looks different to my sister's?"

By answering her questions effectively and learning to talk naturally with your child about her condition, you can help her:

- feel accepted and valued as a person
- build her self-confidence and self-esteem
- answer questions from her peers in a straightforward and matter-of-fact way.

Sometimes parents decide not to bring up their child's disfigurement, as they worry they might upset or scare their child. The children we speak to tell us that they don't mind talking about their disfigurement- they would rather talk about it than have it ignored.

The ideas and suggestions contained in this Guide can help you develop ways of talking with your child about her looking different and ways of explaining it to siblings, friends and other children.

### **1 WHY TALK ABOUT LOOKING DIFFERENT WITH YOUR CHILD?**

#### **Children naturally become aware of difference**

Children are naturally aware of, and curious about, difference. Their curiosity leads them to ask questions about disfigurement, whether it is their own or a disfigurement they notice in someone else.

Children's comments or questions can take you by surprise and are not always polite. But their questions help them to understand themselves and the world they live in. If you can find the words to talk about your child's visible difference with her, you can prepare her to handle curiosity about her unusual appearance with confidence. A child, whose parents have been able to talk to her about her condition, will find it easier to answer questions with simple, straightforward answers like: "It's just a scar from where the doctors fixed my lip" or "I was born like this. It doesn't bother me, or those who know me."

#### **Building a positive self-image**

Your child is likely to encounter reactions of curiosity, surprise or even dislike from others at some point in her life. If you can talk to her about her disfigurement with confidence and in a matter of fact way, you are instilling the belief that her difference is OK.

A positive image of self, that includes not only her disfigurement but also an acknowledgement of her talents, positive personality traits, likes and dislikes, will help her feel confident in social situations.

As a result, negative remarks about her appearance that do not fit with your child's view of herself will be discarded in favour of the storehouse of positive images and beliefs she has built up.

## **Allaying a child's fears or concerns about her disfigurement**

Children 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 her condition (e.g. creams for eczema or birthmarks) and giving explanations to other people in front of her.

Children think in a different way to adults and if her condition is not spoken about directly your child may begin to wonder why. Children are often curious or have fears or worries about their condition. If you quickly move the conversation on when your child mentions her ear or asks a question about why her hands look different she could end up feeling very alone and scared to talk about it. She may also start to dislike this aspect of herself.

Talking to your child about her 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 she can turn to you whenever she wants to share her thoughts, feelings and fears.

## **Preparation for curiosity and questions from others.**

As your child grows older and becomes more independent - going to school, visiting friends without you there all the time, getting ready for secondary school – she will be interacting with a lot of new children and adults.

You may already be aware of other people's reactions to your child's disfigurement and you may already have a collection of explanations and strategies to respond to such curiosity. Providing your child with clear and honest information about her difference and helping her to build up a collection of different explanations and strategies will give her confidence to respond to comments and questions from others when you are not there. This information will also help her to accept her disfigurement as part of who she is and not something to feel embarrassed or ashamed about.

## **A special note about teasing**

Teasing often focuses on differences – size, wearing glasses etc - and children who have a disfigurement may find themselves being teased. This is never easy for a child or for parents. Although the ideas in this Guide may help with teasing, a child should never be expected to cope with this all alone. It is vital that your child knows she can get help from adults around her including her parents and teachers if she needs it.

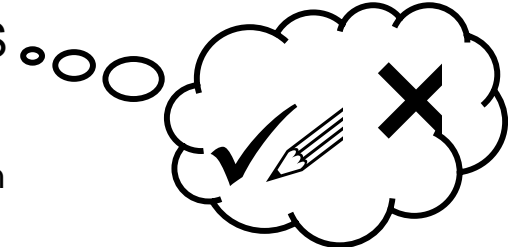
## **2 IDEAS AND SUGGESTIONS FOR TALKING TO YOUR CHILD**

### **Use honest, simple, age-appropriate explanations**

The key to explaining things to children is to keep it simple, be open and honest, and use a language that your child can understand.

## Use words that describe colour, shape and texture

It is helpful to use words that describe what their noticeable feature looks like. Think about the colour, shape and texture of your child's disfigurement. Look at the words in the box below and see if you could use any of them to describe it. The word you dislike may be one that your child or someone else likes. Choose what feels comfortable for you.

**LIST OF WORDS** 

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

Your child can also be involved in finding explanations that she is comfortable with and that she would like the whole family to use. Sit down together with your child and her siblings and discuss possible words you could all use.

At first having a whole sentence or two to say about a child's condition may be hard, so you could both start by just giving it a name:

- This is my small ear.
- This is my birthmark.
- I was born with a hole in my mouth. This is called a cleft lip and palate.
- It is like a mole, only bigger (for a CMN or hairy naevus).

As you all get comfortable using these names and as your child grows older, you can add further descriptions and explanations. Here are some examples that your child could use to explain her difference at school or to friends:

- “I was born with purple mark over my eye and cheek. It’s called a port wine stain.”
- “My eyes look larger than yours because I was born with a condition called Crouzons. I can see as well as everybody else.”
- “This is the scar from the operation I had as a baby. I don’t notice it most of the time.”

## Describe how your child’s condition does (or doesn’t) affect her

Your child may have a hearing impairment in her smaller ear. She may have to wear glasses as a result of a craniofacial condition which affects her sight. She may have “tunnel vision” as a result of Moebius or she may not be affected in any way other than by having a disfigurement.

As children grow, their understanding and interest in their condition increases and explanations should be expanded by providing further information about treatment or medication and how a condition affects their abilities (or not).

Other people, including children at school, may assume that your child is less able just because of the way she looks. By giving her extra information, you are putting her in control so that she feels more confident and assured and less likely to believe what other people think or say about her.

Here are some explanations about appearance or medical related concerns which you can use to describe how your child’s condition affects her (or not).

- “You wear glasses because your left eye doesn’t see as well as your right.”
- “This is your micky button. We feed you through this.”
- “Your trach helps you to breathe. The doctors put it in when you were born.”
- “You have what is called eczema. It makes your skin dry and flaky. We put cream on it to stop it itching.”
- “Your hand cannot 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. The doctors call it Crouzons. That is all that is different. You enjoy playing and having fun just like your friends.”

### EXAMPLE

Children in the school playground comment on Max’s head a lot. Sometimes he ignores it but he wants the others in his year to know that he can do things just like them so that he can join in.

One day, when choosing teams for games he hears a boy say, “Not him. His head will just get in the way.”

He decides to stick up for himself and says, “I know my head looks different but I can still play ball.”

## Use the medical name for your child's condition

Do use the medical name for your child's condition, even it is complicated, so that she becomes confident in speaking about it and does not feel that something is being kept from her. It is likely that she has heard it already in conversations you have had with doctors, nurses, friends and family members and may be wondering what it is all about.

Syndromes or conditions which affect more than one area of a child's body or development can be trickier to explain. To start with, you could describe how the condition or syndrome affects different parts of her body:

- You wear glasses to help you see.
- The machine at night is to help you breathe.
- You were born with your fingers stuck together.

As a child gets older it is helpful to explain that these are all connected. One way of doing this is to say: "You know your hands are different to Mummy and Daddy's and that your head is a different shape to most people's. The doctors call it Aperts."

## Using names like, "special mark"

Many parents come up with positive names for a child's condition like, "your special mark" or "special ear". These are fantastic in helping children feel confident and positive about their disfigurement but it is important to add descriptions and medical names so that they can answer questions about it when they are at school.

If your child can add a little more information and say something like, "I was born with it. It is a birthmark, like a mole but only bigger. It doesn't hurt." she can confidently clear up any uncertainties and move on to normal interactions like exchanging names and playing with the other children.

It is also worth remembering that children may have operations or treatment to change their appearance (removal of a birthmark, corrective surgery, or the reconstruction of an ear). Without further information or descriptions about their 'special feature', they will wonder why their difference, which was so 'special', has had to be changed.

## How you say it is important too

A lot of meaning is portrayed in our body language and tone of voice. It is important for you to practise saying things with confidence, making eye contact and with a body that is not full of tension. We all pick up on body language and if it does not match the content of what is being said, we tend to believe the non-verbal cues! If you can talk with your child about her disfigurement in a confident, matter of fact way, she will have a positive example to follow.

## Talk about similarities and strengths

The tips so far have focused on explaining a visible difference or medical condition. There is so much more to your child that makes her unique and loveable as well as similar to others. It is important to comment on what your child has in common with others, particularly as it becomes increasingly important for children, as they head towards adolescence, to fit in.

When she chats about her friends, comment on what they enjoy doing together (putting on shows or playing the recorder). When she remarks that she hates maths and loves sports, drop in a sentence that shows who else she may know who is like that – e.g. “I was like that when I was your age. In fact, I still hate maths although I try my best to help you with your homework.”

Take time to praise and comment on things you like about your child and compliment her when she 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. Children with a self-image that is multi-faceted, are less upset when a negative comment about one aspect of who they are, is made. In their mind, they know they are worthwhile.

#### **EXAMPLE**

You walk in to her room and find her brushing her hair in front of the mirror. You can take the lead by standing next to her and saying something like, “I really like my bright blue eyes and my smile but some days I don’t like the shape of my nose. What about you, what things do you like about yourself? What don’t you like so much?” You could also comment on the things you like about your daughter, the things she enjoys and the things she does that makes you, and others, smile.

This conversation will let her know that we can dislike one aspect of ourselves and still be a likeable, friendly, loveable person.

## **Finding time to talk**

As your child grows older, her level of understanding will increase and she is likely to want to know more. You may need to sit down for short periods of time to talk. Choose a time when your child is in a receptive mood. If you can, prepare yourself for what you would like to say and think about what she might ask. You may be surprised by the questions she asks you.

#### **EXAMPLE**

Vicki turns to Dad and says, “How come I have one small ear and a wonky face.” In the past her parents had always said, “It’s the way you were born.” Dad decides it’s time to expand on explanations and to give Vicki more information about her condition.

“The doctors call it Goldenhar. This means that your left ear is smaller than your right and one side of your face did not grow properly. You wear a hearing aid to help you hear in your small ear. When you are older the doctors can build you a new ear if you want. If you want to know more about it all you have to do is ask me or the doctor.”

Even though they might be interested in finding out more about their disfigurement, older children might be nervous about talking about it directly so it is a good idea to find a ‘safer’ environment where they think attention is not directly focused on them. A car-ride, preparing a meal, looking at photos, having a bath, clinic appointments, waiting for a sibling to finish a club are just some of the opportunities you can use to talk to them.

If you want to open up the conversation, you could start by saying “I’m wondering what you say to the kids at school if they notice your ear, hand, eye, birthmark or scars? Maybe we could think of some things to say together?”

If it does not seem like a good time for a discussion, try to give your child a short answer and agree a time (e.g. after dinner, next day after school, when the younger children are asleep) to talk again.

Bedtime, when a child is calm and not exhausted, is a good time to talk to her without distractions from younger children. You could start by asking about the good bits and the bad bits during her day. Let her talk in her own time. This is a good way to check in about how she is feeling generally and talk together about how to deal with any concerns.

### **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 her disfigurement.

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

### **4 TALKING TO SIBLINGS**

Older siblings will notice the interest that their brother or sister's visible difference attracts from others. They will be aware of stares or comments made by adults in public and may get asked questions by other children (friends or classmates). They may even be teased about their brother or sister's disfigurement

It is important that simple explanations about their brother or sister's appearance are discussed with siblings so that they too can understand about a particular condition, have their own fears allayed, can accept their brother/sister just the way they are and can feel confident in responding to questions or comments from others.

### **5 TALKING TO OTHER CHILDREN**

Children may comment or ask about your child's visible difference. They may point at it, touch or try to pinch a birthmark, for example, or shy away from a child with a skin condition. At a young age they may not intend to be rude but what they say can come out bluntly or in exclamations of shock, surprise or dislike. Being able to use simple explanations with children can satisfy their curiosity, alleviate any uncertainty and promotes the idea that your child's difference is just one part of who they are.

There are more tips on dealing with other people's reactions and making friends in the *Changing Faces* Guide called *Making friends and fitting in*.

## 6 TALKING ABOUT FEELINGS

### 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.

Start by commenting on how your child's mood seems to you:

"You seem really happy today."

It is helpful to link this to behaviour, body language and facial expressions because these help children to learn how to identify and express their emotions:

"You have a big smile on your face and your eyes are shining. You seem really happy today."

"You were silent and didn't want to talk. That normally happens when something has upset you. I am happy to listen if you want to talk about it."

By offering words to describe your child's feelings, you are providing an opportunity for her to discuss her feelings with you in an open way. She won't always want to speak about her feelings and this is OK. It is enough for her to know that you are giving her the space to discuss her emotions when she wants and that it is OK to feel how she does.

### Restricted facial expression

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

"You look really happy today- your face is lit up and you have lots of energy. Did you have a good day at school today?"

"You look sad today- your eyes aren't as sparkly as they usually are. What went wrong for you today?"

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 her feelings or may misread them. If a child is comfortable expressing her feelings and labelling them for others, she can help those she meets to understand and learn how to read her emotions too.

## Helping your child to express her feelings about her appearance

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

Ask her what it is she doesn't like about her eye (or ear, or scar or lip) rather than why questions as she may not know how to answer this. She may have heard somebody say something about her 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 she doesn't like rather than it being unsaid and developing into "I hate myself because I am 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 she does like about herself 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 herself, look at the *Changing Faces Guide on Finding Further Support*.

## 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 her feelings with you and that she will be listened to with interest, caring and understanding.

## 7 SOMEONE ELSE FOR YOUR CHILD TO TALK TO

As children get older it is helpful if they can have someone of their very own to talk to. This will give them the opportunity to talk about things that they may not want to discuss

with you - they may dislike their disfigurement but be embarrassed to talk about it with you).

As children reach secondary school it is natural for them to share less with their parents and to want and gain greater independence. Encourage your child to talk to someone supportive and suitable with whom she can share feelings, experiences and any concerns. This may be a family friend who she is close to, a counsellor at school, a psychologist or the *Changing Faces*' Young People's Specialist or they may want to go along to a young people's group run by a support group or *Changing Faces*.

## 8 WHAT IF I DON'T GET IT RIGHT?

There are lots of ideas in this guide so allow yourself to take things step by step particularly if this is the first time you are talking to your child about her difference

If you're finding yourself stuck for words, try thinking about how you talk about your child's condition or visible difference now. Do you ever explain it to other people? Do you do this in front of your child? How do you explain visits to the doctors? If you have an explanation for any of these questions then you are already talking, in small ways, to your child about her 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 them know that they can ask questions or talk with you again if they wish.

Remember you don't need to have all the answers. As your child gets older she may have questions that doctors, speech therapists or orthodontists can answer. Don't be afraid to say, "I think it might help if you ask Dr Surgeon that question. I can give you a brief answer now but she will be able to tell you more." Encourage your child to write her questions down and take them with her to the appointment.

## 9 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" 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 only recently have acquired her visible difference or may be undergoing treatment. You may find that your feelings about your child's condition or experience are on your mind and it is difficult to use the ideas. 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 with a visible difference.

You can contact *Changing Faces* on 0845 4500 275 or email [info@changingfaces.org.uk](mailto: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.