

11-16 years. Supporting a child with a disfigurement: a teacher's guide

## Guide 5. Having something to say

On first encountering someone with a facial disfigurement, everyone feels surprised or disconcerted, and also curious. Younger children will usually stare or ask direct questions - "What's that thing on your face?" In due course they are taught that it is rude to stare or ask this kind of question – though this may not stop them doing it. At secondary school, young people will find themselves staring, perhaps more furtively, or looking away, when they encounter someone they haven't met before with a facial disfigurement.

Even as adults, upon meeting someone with a facial disfigurement, we are likely to have to grapple with our reactions of surprise, curiosity and unease, and to find ourselves noticing their appearance in a way which we imagine must be uncomfortable for them. All this is happening at the same time as we are attempting to greet and speak 'normally' to the person who looks different.

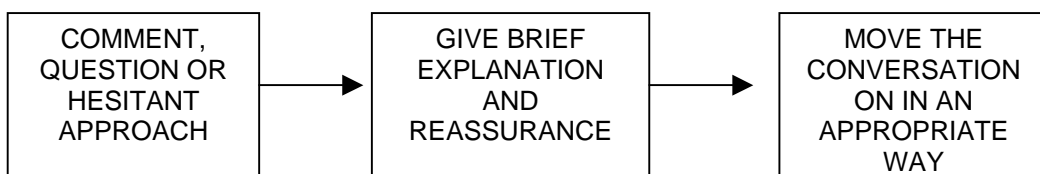
All the research into the social experiences of people with disfigurements indicates that things work better socially if the person with the disfigurement uses responses to staring which include tolerating some initial curiosity, even if it seems like 'staring', and saying something very brief about the way they look. This gives other people – who cannot but notice the disfigurement – a moment to settle their thoughts after which ordinary social interactions can flow more comfortably.

As a teacher you are well placed in the social environment which school affords, to help your pupil develop effective coping strategies for managing other people's curiosity, concern and staring.

### 1 WHEN MEETING A NEW PERSON

To make a positive and effective response, people who look different have to:

- recognise that an initial response of surprise is normal and is not an expression of deliberate unkindness\*
- respond with just enough information and reassurance to enable the other person to settle their thoughts
- move the conversation on in an appropriate way to a related or a different subject.



People who have a facial disfigurement usually find that they get on best when they take the initiative with each new person's reaction to their unusual face. It takes time and practice, as well as courage, to learn to do this.

\* Everyone with a facial disfigurement has occasionally encountered people whose behaviour was clearly unkind or unpleasant. In this case it may be best to withdraw from the situation and do something positive to get over the shock or hurt feelings. It is also useful to remember that most people are not usually deliberately rude and will respond well to the social skills outlined in this *Guide*.

## 2 DECIDING WHAT TO SAY

Ask the student you are supporting what kind of things he says or would like to say if someone asks in a reasonable way about his unusual appearance. It may be useful to talk generally to open up the subject area.

- Is your student able to talk to others about their disfigurement?
- If it is a condition present since birth, does it have a name?
- What about treatment, in the past or still to come? What does this involve?
- If this student has had an illness or injury which has affected his appearance, can he say something about this?

Help your pupil to explore options and arrive at some words and phrases which feel reasonably comfortable. (The initial response can be changed or updated at any time so the words and phrases you work on here are just to get things started.)

Here are some examples which others have used:

- Don't mind my face, it's just the way it is...
- I was in a fire a couple of years ago but I'm okay now...
- Don't mind my skin. You can't catch it. It's a bit like eczema – much too dry all the time...
- I was born with a cleft. It's fairly common. They fixed it with surgery when I was a kid but it leaves a scar.

Over time your student will develop a more extensive range of responses – usually including humour and other less conventional options. They will be able to choose which approach to use in different situations.

## 3 MOVING THE CONVERSATION ON

This is a key part of responding positively to other people's reactions to unusual appearance. It enables the young person affected to gain some control over how much attention goes on his appearance and at the same time to show something about himself as a person.

Young people with disfigurements find the following kinds of follow-ons particularly useful.

### Showing an interest in the person who asked

"It's called Crouzon's. It just affects the way the bones grow in your face, cheekbones especially. But it's cool to be different. What's different about you?"

"It's a scar from when a dog bit me. Have you ever had an injury or been to hospital?"

### Maintaining conversation but changing the subject

“I was in a fire but that was ages ago. I missed my bus – I’ve got to sign a late book or something. Do you know where they do that?”

“It’s just a birthmark – I always had it. Cool trainers – where’d you get them?”

“I was born with a cleft lip but they fixed it when I was a kid. It’s just a scar. Did you watch the football last night?”

“It’s my vitiligo. It makes bits of my skin change colour. It’s not catching. Are you going to the canteen? I left my lunchbox at home this morning.”

### Ending the conversation

“It’s eczema. Dry skin, that’s all. You can’t catch it. I think I heard the bell. See you around.”

“It’s just the way my head is. Think of it as modern art. I mustn’t be late. Bye.”

#### A case study

Maria had talked to her class about the eczema which affected almost all of her body, and no longer felt anxious about being seen in the changing rooms at school. However, when she went swimming, others were inclined to stare. First she tried saying, “It’s just eczema. You can’t catch it. Please don’t stare.” This sometimes worked if she was being stared at in a bus queue or out shopping with her parents. But it didn’t work so well in the pool.

So she talked it through with the PE teacher (who had always been very encouraging about joining in everything) and some close friends. Together they worked out a few things that Maria could try saying. These included, “I’ve got eczema. It doesn’t stop me smiling.” and “I know I look a bit boiled but you can relax – it didn’t happen in this pool!”

In addition, the PE teacher agreed to send a message round to his colleagues at other local schools, asking them to find an appropriate opportunity to relay some ‘citizenship’ information to all their pupils (any of whom might use the local pool) - “Eczema is a skin condition causing dryness and soreness but you can’t catch it. If you find yourself staring, it works quite well to smile and say hello as well.”

## 4 PRACTISING AND GOING LIVE

Your pupil will need opportunities to practise by role-playing with a partner and taking turns to be the one who stares and the one who looks noticeable. Pay attention to body language and voice tone:

- Eye contact is important. If this is difficult a useful alternative is to look at the other person’s face between their eyes, at the bridge of their nose.

- Stand straight in a relaxed, comfortable-looking way, so as to appear neither aggressive nor timid.
- Speak firmly and clearly with appropriate pace and volume.

If the pupil has been in school for some time there may not be many opportunities to practise 'for real'. Encourage the use of this important social skill -

- at the start of each school year when new pupils and staff have join the school
- when meeting a new supply teacher
- on school trips
- during sports, music and drama activities involving pupils from other schools.
- at weekends and during school holidays.

Naturally, some young people are much more socially fluent than others and you will judge how much help your pupil needs with their 'scripts'.

## **5 CONSIDERING SIBLINGS**

Many young people who have disfigurements have a brother or sister who gets comments and questions about their sibling's difference. They can learn to deal with curiosity, concern and comments by using the techniques of prepared responses described above. For more about how a young person's disfigurement can affect brothers and sisters, see the *Guide on Working with Parents and Siblings*.