

7-11 years. Supporting a child with a disfigurement: a teacher's guide

Guide 5. Having something to say

Children can be forthright with their curiosity and will ask direct questions such as “What’s that on your face?” Many adults subscribe to the commonly held belief that personal remarks are rude and that a visible difference should never be noticed or discussed. As it is not nice to be stared at, parents often tell their own children not to stare.

But children often avoid staring by turning away from the child who looks different. The child with a disfigurement will then find it harder to play socially and make friends.

All the research into the social experiences of people with disfigurements indicates that it is more helpful for the person with the disfigurement to have 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 puts other people – who cannot but notice the disfigurement – at their ease and enables ordinary social interactions to follow.

1 MODELLING EFFECTIVE RESPONSES

Much of what children say and do comes from watching and experiencing adult behaviour. By responding effectively whenever anyone stares or asks questions about your pupil who looks different, you and your colleagues will achieve the following:

- Your pupil will learn to manage other people’s reactions in ways which are socially positive.
- You will help the child to understand that new people cannot help being concerned or curious and that a potentially awkward situation can be handled in a straightforward way.
- Your responses will enable everyone to learn how to take difference in their stride.

Having no response prepared leaves a child at risk of reacting anxiously, defensively or with annoyance – leading to unsatisfactory social interactions. To make a positive and effective response, this is what people who look different have to do. This is what you need to model for your pupil:

1. Recognise that an initial response of surprise is normal and is not an expression of deliberate unkindness
2. Respond with just enough information and reassurance to enable the other person to settle their thoughts
3. Move the conversation on in an appropriate way to a related or a different subject.

Modelling an appropriate response is useful even when a child who has a disfigurement does not seem to be aware of other people’s reactions to her unusual appearance.

2 DECIDING WHAT TO SAY

Find out if the child already uses a specific form of words to describe their unusual feature, e.g. 'It's my birthmark'.

If not, you will need to work with the parents to find words and phrases that feel comfortable. This calls for sensitivity. There may be painful issues for parents about what has happened to their child, or concerns about diagnosis and medical language. Parents may have their own cultural outlook that will have a bearing on their preferences.

It can be helpful to draw up a list of all the things you and the parents (and the child if she's ready) can think of that it might be good to say, and then pick out the ones which seem to work best. Here are some examples to get you started.

- That's just the way Millie's face is.
- John has a scar. He was hurt but he's OK now.
- Zak has one ear like yours and one folded-up ear.
- Jemma has had a pink mark on her face since she was a baby.
- It's got a long medical name so it's called NF for short.
- No, you can't catch it.
- Yes, I think it does get sore. Milo has to keep putting special cream on his skin.

Go through the ideas that you've developed together with your pupil and her parents and allow her some time to see if she has a preference. What would she like to say if someone asks her about the way she looks? If she wasn't involved directly in the discussion above, give her the options you and the parents have arrived at. She might like to try out different responses before choosing. You could play out situations together like a 'pretend' game or write the responses on small cards so that she can have them one at a time for a day or two to see how she feels about each one.

At first it is best if everyone uses the same simple form of words, both in and out of school. Over time a more extensive range of responses will be developed and can be selected to suit different situations.

3 MOVING THE CONVERSATION ON

This is a key social skill to model as part of 'having something to say'. When the child is ready to do this for herself, she will gain some control over how much attention goes on her appearance and at the same time show something about herself as a person.

Showing an interest in the child who asked

Teacher: "That's just the way Jemma's skull is. Is your skull smooth as a ball all over or can you feel any little ups and downs?" (Run your fingers over your own forehead and scalp too!)

Child: "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

Teacher: “Jamie was in a fire but he’s okay now. Would you help me cart this gear back to the PE cupboard?”

Child: “It’s called a birthmark – I always had it. Do you want play footie with us?”

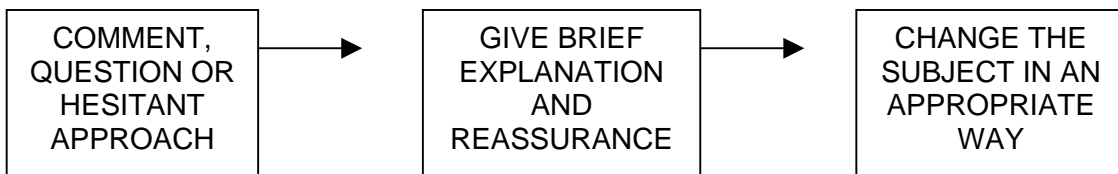
Ending the conversation

Teacher: “Naomi has eczema. It makes her skin very dry and sore. You can’t catch it. Do you want to get your coat and go out to play?”

Child: “It’s just the way my head is. My Mum’s waiting for me – see you.”

4 GETTING EVERYONE INVOLVED

All staff at your school including kitchen staff, lunchtime supervisors, parents who help, supply teachers, the school caretaker and the lollipop person, need to be able to ‘model’ the process of taking the initiative wherever the situation requires it, giving a brief explanation, and moving the conversation on to something else. This can be presented to staff as part of a meeting, ideally before or very soon after the pupil joins the school. It will also be useful if the pupil has had or is having medical treatment that affects their appearance. Staff will need to know what to look out for, how to respond, and how to move the conversation on naturally.



They will need the exact form of words which has been agreed with the parents and the pupil herself. They will also need examples of how to move the conversation on in each of the three ways described in section three above. You might judge it appropriate to run off an information sheet about this as a handout for everyone.

Occasionally a staff member will need to override a strong inclination to handle the situation in a different way, perhaps because they are uncomfortable or believe it is wrong to talk about disfigurement in this way. It may be useful if staff can read some of the *Guides* from this set, eg the *Introduction* and *Starting junior school*. The *Changing Faces* booklet *Facing Changes* can be very helpful too.

If staff doubt the need for ‘having something to say’ because the pupil is known and accepted by everyone they meet at school, it will be important to emphasise the child’s needs beyond school and the school’s obligation to teach with these needs in mind.

- School trips
- Sports, music and drama activities involving pupils from other schools
- Weekends and school holidays
- A new pupil or member of staff joining the school, including supply teachers.

The ability to manage interactions with new people is a key social skill for anyone who has a noticeable appearance, and a key social skill for making friends.

5 WHEN THE PUPIL IS READY

All children want more independence as they get older and a child with an unusual appearance is no exception. Through effective modelling as described above, some children just 'pick it up'. If you do not see this happening, arrange for the pupil to learn and rehearse in a 'safe' situation, e.g., role-play, to gain confidence in using planned responses. You or another staff member could give this help. Alternatively, arrange for your pupil to work with one or two classmates who are good at acting. Obviously, they need to be able to work with each other in a friendly and constructive way.

If or when the child who looks different is able to give her own response to comments or questions, notice how her interactions develop. Some children are much more socially fluent than others. Judge how much help your pupil needs with her 'scripts'.

From time to time, check the form of words with your pupil and her parents. Be ready to devise new words and phrases as required.

6 CONSIDERING SIBLINGS

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