

# **Starting School**

When children and adults understand what a condition is and how it affects a person, they are much more likely to accept it and not pay too much attention to it. Facial palsy is there for everyone to see, it cannot be a secret and it should not be a mystery. At the same time we need to respect the feelings of the child as they may not welcome attention relating to their condition. In our experience children start to become more self-conscious about their differences in Year 1 or 2 and Reception is the best time to normalise facial palsy.

## **Communication is key**

Facial palsy should be explained to all staff including teachers, teaching assistants, admin staff, catering staff, playground and lunchtime supervisors. You will also need to give school photographers advance warning.

## About my child's facial palsy:

It was caused by
About my child's likes and strengths (include examples of achievements)
It affects their ability to:
☐ Smile on one/both side(s)
☐ Close one eye
☐ Close both eyes
□ Eat
□ Drink
□ Speak
□ Hear
☐ Show facial expression
Other comments

# Other information about my child

Staff handling of questions	
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My child has social or learning needs as follows:	
My child has medical or functional needs as follows:	

If someone asks questions about my child's facial palsy, this is the answer I prefer to give:

School staff may be asked questions about facial palsy, it is best to address these as simply as possible and then move the conversation on to normalise things. Here are some examples of responses:

"Molly has a missing nerve in her face, it's called facial palsy. You can't catch it. Shall we ask Molly to help us collect the books?"

"We all smile in our unique ways, think about any pets you have; you can tell when they are happy, can't you?"

"Molly's eye rolls up to keep it safe. People wear sunglasses to keep their eyes safe from the sun. Shall we get the pens out now?"

# Helping the child to respond to questions and/or enquiring looks

Children are naturally curious when someone's appearance is unexpected. When an adult is faced with their child staring at someone with an unusual appearance, often the response is to discourage them and tell them not to stare. We believe that it is more helpful to the child with the facial difference to learn positive responses to this kind of behaviour. It is something that could happen throughout their lives and we want them to learn to tackle these situations with confidence. By learning how to answer questions the child is taking the mystery out of the condition and normalising it.

School staff can play their part in helping children answer questions, rather than shying away. This will provide firm building blocks for the child's future self-esteem.

Examples of things to say

"One of my eyes doesn't blink, but I can also raise just one eyebrow!"

"I just smile on this side, but all of me is happy! Shall we go and play now?"

"I don't smile with my mouth, I smile on the inside, just like a cat!"

"It's called facial palsy, there are lots of other people just like me."

#### **School Photographs**

People who grew up with facial palsy regularly tell us how difficult school photograph day was for them. Staff should speak to the school photographer before school photograph days to ensure they are aware if a child cannot smile or smiles differently. They may mistakenly assume a child with facial palsy is smiling differently on purpose and reproach them for it. At the same time the photographer should not single the child out in any way.

#### Other issues

A child with facial palsy may not be able to play the recorder, if your school is using recorders please consider mixing them with other instruments. The child may find it difficult when you ask the class to close their eyes. Speak to the parent and find out whether they would prefer you to ask the class to 'cover' their eyes rather than close. The catering team may want to keep some straws handy or be on hand to help cut an apple up. Make sure all staff are aware of potential issues; as every child with facial palsy is unique they should discuss this with the parents.

# Don't make assumptions

Facial palsy on its own does not affect intellect. Read up on the work of Dr Kathleen Bogart, an Assistant Professor in Psychology who was born with Moebius syndrome, a condition which caused her bilateral facial paralysis, meaning it affected both sides of her face. Other famous names with facial palsy are John Hayes, MP for South Kesteven and Jean Chrétien (former Canadian Prime Minister).

Many people who grew up with facial palsy report being paired with quiet children or children with other disabilities at school. This can make children feel more isolated and singled out. Bear in mind that they may not want to put their hand up in class because this is drawing attention to themselves. The earlier you can encourage a child with facial palsy to get involved the better.

# **Bullying**

Take all reports of incidents seriously. It can be hard to relate to how upset a child can feel when being teased about their smile, especially if you think it is not that noticeable. Bear in mind that the child does not see their own animated face, they only have pictures or video or the words of others to go on to form a picture of their face. When some children are bullied or teased about facial palsy, their automatic reaction is for them to try to hide their smile. If staff find it hard to relate to this, ask them to spend a day of their weekend actively trying not to smile, and then you may understand the devastating impact unchecked bullying can have. With unilateral facial paralysis you can see if a child is feeling self-conscious by the way they smile. If they are producing tight little smiles rather than relaxed ones then you need to work on their self-confidence in a non-intrusive way such as encouraging new friendships, buddying up, etc.

When dealing with the perpetrator, seek to educate rather than punish. Often children are curious and if you teach them more about the condition, they will be armed with new information. Be careful not to create an environment of pity.

Children who share information confidently about facial palsy in class or assemblies often cope better. While we don't promote singling children out as 'different' we believe that encouraging children to talk about activities they have taken part in, as part of the charity, for example, can help. Getting information out into assemblies (via the child) also helps the rest of the school to understand more about the condition. Be mindful that bullying often occurs on the playground with different year groups and a child with a visible difference will be at higher risk.