



Coping with People's Reaction

to your child's SWS, PWB, or KT



THE INFORMATION IS COURTESY OF CHANGING FACES.



Introduction

Other people may react to your child's appearance. Some people may stare, ask questions or even comment. These reactions and the loss of privacy can be difficult. Yet everyday life has to go on. What you do and what you think when you are around other people can make a big difference. There are some simple strategies that can help you to boost your confidence and hold your own with other people. They can put you, your child and other people at ease and make awkward situations easier. It is important to reassure other people that you are coping, and that you and your child are normal. If you are okay and coping, then your confidence will radiate. The way you are with your child in public will say a lot to people around you. Your child will also learn from your example, from the things you do and say, as well as from your attitude.

Be positive.

Other people don't normally mean any harm. Although it is no excuse for being rude, they are mostly just uncertain or curious. Often they don't know what to do or say. Unusual situations can make us all uneasy and other people might need some help and time to feel comfortable. Try not to let other people's ignorance or curiosity get in the way and try to concentrate on the good things that happen. At the same time, be realistic. People will notice your child's appearance if it looks different and they may look at your child for longer when they first see him or her. You probably have to expect this.

If people stare repeatedly and start making comments, you may need more than just a positive attitude - there are some suggestions for coping with this kind of problem in the next section.

What You Can Do or Say

Reassure

Reassure the other person. Let the other person see that you are human – why not smile and say hello? A smile, a nod or a wink can work wonders. Don't be afraid to look people in the eye. You will appear more confident and feel more in control.

Distract

Distract the other person. Sometimes you can feel on show, like when you're waiting for a bus or in a shop. This is an ideal time to distract the other person from your child's appearance, and show them that you're normal. e.g. "That's Michael's favorite toy. He won't go anywhere without it." Or chat about something generally – "I'm glad we chose the shortest line!" Young children who are staring often respond well to a smile and a chat. Ask them their name, introduce your child (if they are young) or just say, "Hello."

Explain

A simple explanation about your child's appearance can reassure and educate other people, especially if they appear anxious.

"Nathan has a port wine stain. It doesn't hurt and you can't catch it."

"I see you're wondering about Sara. She just had a laser treatment, but she's OK."

How much you say is up to you. You can say what you want and then distract the other person by chatting about other things, or just move away.

Be assertive

Stand up for yourself, without being aggressive. It is OK to let other people know if they are being hurtful.

"My son has a port wine stain and I'd rather you didn't stare."

Use humour. This can break the tension and put people at ease.

"You should see how she looks at people she doesn't like."

"John's not looking his best today."

Think about something else. It can help to busy yourself in a task with your child. Focus on chatting with your child, or working through the shopping list together.

Tell yourself it's okay. What you say to yourself can make a big difference to how you feel. Think up something to reassure yourself with.

"I can cope with this."

"There are bound to be some tricky people out there."

This sort of reassuring thought can help to carry you through.

Sounds Overwhelming?

Take things a step at a time. A good beginning would be to make a list of annoying things that people say or do. Then sit down with a friend or your partner and come up with as many responses as you can for each of these situations. Choose the answers you like the most, and practice them. Of course, the way you say and do these things really matters. Your body language and tone of voice are all part of the message you are giving. Look people in the face and don't avoid their gaze. If you say something, speak clearly and brightly. All this will help to show people you are confident. Remember you don't have to be perfect. It is OK to make mistakes. You can try again next time.

Support for Your Child

As a parent there are many practical ways that you can build your child's self esteem and confidence. Many of these things are important for all parents and children. As well as providing the love and support that all children need, there are also some extra ways that you can support your child when he or she has a visible difference or disfigurement.

Spend time with your child regularly.

Do something that your child enjoys. Telling a bedtime story or playing a game together are simple ways of building your relationship and having fun together.

Listen to your child.

Be there to hear about their day and what has happened. Children often show their feelings in their behavior rather than by talking. Watch and listen to what your child is telling you in words and actions. You can help your child to understand and manage feelings by listening and accepting his or her feelings. If your child is upset, let it be known you've noticed and help your child to find the words to understand his or her feelings. You could say something like: "That makes you very upset, doesn't it". If your child does talk about feelings you can acknowledge it by saying: "You feel really angry about what David did, don't you?"

Comfort your child.

It can be tempting to try and make things better for your child, yet listening to and comforting them is often enough. It will be hard for your child at times - and it is okay for them and you to feel upset. Children also need to know that they can cope. By accepting your child's feelings and guiding them towards finding their own solutions, you can show your child that they can cope. Talk about your child's appearance. Be open with your child about his or her appearance and answer any questions honestly. It is okay to use other words to describe your child's condition, like 'your special mark', but do use the correct name for the condition as well. This will help your child to explain about the facial difference to other people and to deal with other people's curiosity. Give information appropriate to your child's age. This may need to change as your child gets older. By talking openly with your child, you can encourage him or her to talk to you when necessary. Children will wander off or change the conversation when they've had enough. Questions often come up in the middle of other things. If that is not a good time for you, remember to raise the question with your child at another time. Don't just leave it unanswered. Tackle teasing. It is good to tackle teasing and name calling directly. Here are some ideas both for preventing problems and for dealing with them should they arise.

Support for Your Child

Praise your child for coping.

It is good to notice awkward situations that have been handled well. It will build confidence and positively reinforce the action.

Talk about name calling and teasing.

Ask your child occasionally if things are going at school and provide opportunities to talk about any concerns.

Teach your child a simple sentence about their face.

Just as it helps to be prepared, it can also help your child. Think up a simple sentence "I just had a laser treatment to make my birthmark lighter" or "I've got a birthmark "; My face is just different, that's all." Help your child to learn this sentence off by heart. The way your child says their sentence is important too. Try using a puppet or a doll to help young children use their sentence. Have fun with it until your child looks and sounds confident. It is helpful to have a collection of responses ready for teasing.

Children can also learn what to say from a young age by hearing you answer other people's questions. As your child gets older, check what people are saying about the facial difference. The answer may need to change as the time passes.

Communicate with your child's school.

Children can be self conscious about their appearance and questions and comments from other children can be tricky to deal with. Many problems for children tend to be around school and talking to the teachers early can prevent problems later on.

Starting a New School

Some things to think about before your child starts a new school include:

- Where do the local children go to school?
- How far will your child have to travel?
- How big is the school (how many pupils)?
- What is the school's policy for dealing with teasing and bullying?
- Are there other children with special needs at the school?

A school which has other children with special needs may have effective policies for dealing with teasing and bullying. It may also be more accepting of difference and more aware of difficulties. It is a good idea to visit the school before your child starts and to meet the head teacher. Once your child has started at school, it's good to minimizing changing schools, so that your child can stay with good friends.

Talk to the teacher.

If you are worried about anything at school speak with your child's teacher. If you make an appointment it will help the teacher to give you complete attention and will give you a better opportunity to voice your concern. A hurried comment as you pick your child up from school won't be as effective and the teacher is more likely to dismiss it. Be specific about your concerns and give examples. "The other children give Sara a hard time" is not as clear as "Other children ask Sara lots of questions about her face. They don't give her time to explain. She's tired of the questions and unhappy at school. I'd like your help in doing something about this."

It is easy to assume that your child's teacher already knows what is happening. Teachers do not see everything.

Persistent questioning may not concern a teacher as much as teasing or bullying, yet this questioning is often a problem. The school can then address the situation specifically. Most schools are supportive when you make your concerns clear. It might take a while for the problem to be sorted, but you should persist until it is addressed.

Telling the Story.

If other children are asking questions, or teasing, it might help for them to find out more about your child's appearance. Explaining once and for all can help get the curiosity out of the way and answer the questions other people have. If your child is young, the teacher or another adult (maybe you) could speak to your child's class about what has happened to your child. Your child may like to be part of this or they might prefer not to be there. Either is OK.

Older children might choose to do this by themselves. They could prepare a project, show a video, or just speak to their class. Telling the story can also prevent problems later. For example, it has worked very well for children who have had an injury and are returning to school after a long time away. Remember this approach should only be used if your child is comfortable with the idea. Always discuss things with your child (and the teacher) before deciding what to do.

Encourage Independence

Letting go and letting your child do things for themselves is a challenge that all parents face as their child grows older. When your child has a facial difference, you may feel more protective. It can be hard to know how protective to be and how much is too much. One way to think about this is to compare your child with other children their age. Hopefully, with a little support from family and friends, you will be able to offer the same independence to your child as any other child of a similar age.

Encourage older children to find out more about their condition.

This can help them make the information their own and understand their medical care and begin to take their own decisions.

Encourage your child to develop talents and interests.

Having an interest or hobby from an early age can help children to feel good about themselves. Other people will also notice your child for skills and talents and not just for having a different face.

Encourage your child's friends.

Having friends is important for any child. Support your child in making and keeping friends. Invite friends over to play and encourage your child to join in activities where new friends can be made. If you and your child feel it's important, both of you can explain about your child's looks before joining any other group.

Messages about Appearance

You and your child will be surrounded by images of how people should look in advertisements, films and stories. These often give the message that to be happy, successful and popular you have to look just right. As a parent, you can challenge these ideas with your child. Happiness does not have to depend on how you look. You can help your child to realize that personality says more than appearance and that they have a lot going for them. In this way, your child will learn to value himself or herself, with abilities, talent and personality.

Help your child respond to other people.

Your child will learn a lot from the way you do things. How you respond to other people will set an example for them. The more ways you have for dealing with other people, the more your child will learn from you.

Let your child respond to other people sometimes.

Watch for signs that they want your help and don't force them to go it alone, but do encourage them to handle the situation themselves at times.

Introduce your child to a variety of other people.

Other people can be an encouragement for you and your child and help you both look toward the future positively. Meet others with a similar condition. Support groups are one way of meeting other people. Collect toys, books, news articles and videos, showing people who have coped in challenging circumstances and which give a positive message about appearance and difference.

Get involved in the school and the local community.

Being part of the school and local community is a good way to get to know other people and to show other people that you and your child are OK. Make the most of your child's appearance. There is much more to your child's appearance than a birthmark. Encourage your child to take pride in his or her appearance. A trendy hairstyle and fashionable clothes will go a long way toward boosting confidence and can promote acceptance by other children too.

What about make-up?

Make-up may lessen your child's birthmark. It can also highlight your child's other features to make him or her feel good. Older boys and girls might want to use make-up on special occasions. Make-up is not necessarily a good idea for young children, as it could give them the idea that they are only OK when wearing it. Trained beauty therapists can advise you on the types of cosmetic and concealing make-up available and how best to use them.

Keep a diary with your child.

Include the times spent in hospital and any treatment as well as other things that are happening. Photos and mementos help record what has happened. They can help your child to build a positive picture as a person and to see hospital visits and treatment in the context of everything else. Diaries are important for older children too. They are an opportunity for private thoughts and sorting out feelings.

Siblings

Brothers and Sisters

It is important to talk to and involve brothers and sisters about any their sibling's appearance. They need basic information that allows them to understand their brother's or sister's medical condition. They should also be encouraged to ask questions and talk about any difficulties or fears. Siblings often get asked about their brother or sister and sometimes get teased. Help them to develop a sentence of their own that provides others with a simple explanation about their brother or sister. From time to time, check out with your children how things are going for them. Involving the whole family will benefit everyone, and increase their understanding of difference and their sibling's medical condition.

If your child needs extra support.

There may be times when you know that your child is unhappy, or you may notice a change of behavior, such as bedwetting, disruptive behavior, starting to stammer, reluctance to go to school or avoiding certain activities. If you notice changes in your child's behavior or are aware of difficulties, do try to find out what is going on. Talk to your child. Let it be known that you are concerned and make a point of listening and being there.

It is OK to ask for help.

It is not a sign that you are being a bad parent or not coping if you or your child needs extra support. You may be able to tackle the difficulty with the help of your child's teacher. Your GP can refer you to a child psychologist who can help you and your child.


Acknowledgements

Thank you to Changing Faces for this information. You can learn more about this organization at:

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The Sturge-Weber Foundation's (The SWF) global mission is to improve the quality of life and care for people with Sturge-Weber syndrome and associated Port-Wine Birthmark conditions through tenacious collaboration with clinical partners and pioneers, education, advocacy, research, and friendly support.

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