



Bringing up a child whose face looks different

Information for families

Great Ormond Street Hospital
for Children NHS Trust

This leaflet contains information about helping and supporting children who have a facial disfigurement. Much of the emphasis is on birthmarks, but the information and advice is relevant to all children who look different.

Society places a lot of emphasis on physical appearance. While it is quite normal for us to notice things that are different about others, if your child has a visible birthmark which makes them stand out from the crowd, you may have understandable concerns about how they will cope. And as a parent, you may be upset if people comment on your child's appearance, or are even rude about it. Some children may also have related medical complications that can add extra worries and demands.

You will meet various challenges as your child gets older, and at times you may be unsure about what to do. This leaflet aims to help you, and is based on things that other people whose children have birthmarks have found useful. If you would like more information on any of the issues mentioned here, there is a list of useful contacts at the end.

Your feelings around the time of the birth – and what to do

If you see a mark on your newborn, or notice one that changes shortly after birth, you may experience a variety of feelings - there are no right or wrong reactions. For some people the birthmark may not be a big deal. For others, seeing it can come as quite a shock. It can take getting used to and it is natural to feel unsettled and uncertain.

You may decide to try and find out as much as you can about your child's condition, or feel angry, depressed or even guilty.

The most important thing is that you give yourself time to adjust to the new situation. Having a new baby to look after is an enormous challenge in itself.



Some or all of the following ideas may help if you find it a difficult time:

- **Celebrate your child.** There are many wonderful things about a baby who happens to have a birthmark. A newborn baby is much more than just the way they look.
- **Find out everything you can about your child's birthmark.** This will help you understand what is happening and what to expect for the future. You can start by asking your GP or paediatrician and you may want to ask for a referral to a specialist. Make sure your doctor answers all your questions clearly – you may find it helpful to write them down before your appointment so you don't forget anything.
- **Talk to someone else whose child has a birthmark.** You will be able to share experiences and get helpful tips. See contact details for The Birthmark Support Group and others at the end of this leaflet
- **Look after yourself.** Your own needs are important too. Keep in touch with friends and take time to relax and treat yourself. You are going through a difficult time, practically and emotionally.

How can you cope with other people's reactions?

Be positive! You may feel uneasy when out in public or visiting friends and relatives for the first time. People are often curious about your child's birthmark, or may not know how to react to it, and you may feel that they're being rude. Try not to let it get to you and concentrate on the good things that are happening. Here are some suggestions of things you can say or do at difficult times:

- **Be polite, friendly or even humorous.** A smile or a joke may be all it takes to reassure the other person
- **Explain.** It can help to have a simple explanation prepared that you can use when people ask you about your child's birthmark
- **Talk to the other person.** When you're feeling like you're on show, start up a conversation to show that you really are normal
- **Be assertive, but not aggressive.** If people are over-intrusive or rude, it's OK to let them know they've gone too far
- **Think of things to help you keep your cool.** You may want to concentrate on chatting to your child or working through your shopping list.

Challenges and solutions during the pre-school years

This is an important time for developing coping skills and self-esteem in yourself and your child. These are the years when children become more aware of the world around them, and of being different, and start to ask questions on just about everything. These years are an opportunity to establish good lines of communication between yourself and your child. Talk openly and honestly about everything, including his or her appearance.



Children are already learning how to cope with the big wide world at this stage. They'll need your guidance with many things, including how to cope with reactions to the way they look.

Some or all of the following ideas may help if you find it a difficult time, or sense that your child is:

- **Showing your child how to cope.** Children at this age learn by watching other people, especially those close to them. Your child will learn how to manage things like hospital visits, making friends and coping with other people's reactions by watching you. The best way of teaching your child to cope well is to cope well yourself and to introduce him or her to other adults and

children who also cope well. The Birthmark Support Group and others listed at the end can help to put you in touch with people.

- **Talking to your child about his/her birthmark.**

Parents often ask what they should tell their child about their birthmark. You should be open, honest and calm, and use simple terms that they can understand to explain about their birthmark and any treatments they might be getting. All children differ in what sort of language or explanations they find easiest to understand. If you're not sure that they're clear about what you've told them, ask them. You may have to find other words for some part of your explanation. By talking openly and honestly, you can **prevent your child** from making up their own mind about what's wrong. For example, that 'I have a mark on my face because I'm bad.' Understanding their condition will help to alleviate any worries or false ideas that they may have, and it will also help them to come to see their birthmark as just another part of themselves, like their hair, their eyes and all the other things that make them who they are. They will also learn that it is OK to talk about their birthmark.

Challenges and solutions during the early school years

This is a time when your child will go into new and unfamiliar environments, and meet lots of other children. They will also have less adult supervision than before. Some children may ask questions, stare or comment. This isn't surprising, as this is also a time of great change for their classmates, who are meeting lots of new people too.

This is the time when your child starts to develop a sense of who they are. It's very important that they learn to appreciate who they are besides someone who has a birthmark. Very occasionally, birthmarks affect some aspect of your child's function, such as vision or movement (ask your doctor if our booklet *Sturge Weber Syndrome: information for families* is relevant and might be useful.). If this is the case, or if there are special care requirements, these differences will be especially apparent once your child starts school and compares him or herself to the other children.

Some or all of the following ideas may help at this time:

- **Preparing your child.** It's a really good idea to do this before they start school. You should explain to your child that other children might be interested in why they look different, and practice with them some ways of responding to questions and comments. Simple answers like "It's just a birthmark. I was born with it" can be all that's needed to satisfy other children's curiosity. Your child may get a real confidence boost from practising responses like these with you before they are asked questions.



- **Preparing the school.**

Teachers and other staff may never have met a pupil with a prominent birthmark before. They can find it very useful to be prepared before your child starts school. Talk to people at your child's school about the best way to do this. Some parents distribute information or arrange a talk to the class or the school about birthmarks. Children who have not seen birthmarks before can think that the mark is catching or somehow threatening and might avoid your child because of these false but natural fears. Like adults, they may merely be curious or uncertain about what to do. Educating the adults and children at school is often a good way of satisfying curiosity and stopping social difficulties before they happen.

- **Supporting your child.** You need to do this in an ongoing way, because they may need a boost from you at any time. Be ready to be supportive with a chat, a cuddle, a laugh or some good advice when necessary. Coping with the situation is a skill like any other, and just like playing football or doing maths, with good teaching, practice and encouragement, your child can become very good at it. If your child gets attention or comments that they find upsetting, be sympathetic and help them to deal with the situation calmly and sensibly.

- **Developing your child's strengths and building self-esteem.** Encourage your child's interests and efforts in whichever activities they seem to enjoy. Give them lots of feedback and praise so that they know that they're a great person and that there is a lot more to them than just their birthmark.



Challenges and solutions during primary school and transition to secondary school

As your child gets older, they will continue to develop their own personality and their independence will gradually increase. When they're at primary school, they will base the way they feel about themselves more and more on their skills and school achievements. They will compare themselves with their classmates over things such as their handwriting, maths ability, football or dancing skills, rather than on looks alone.

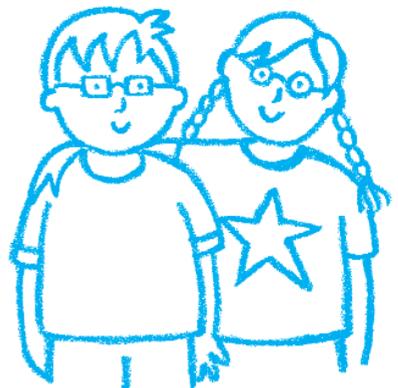
Friendships can become very important for children at this age. As well as being fun, friends can boost self-esteem, be a source of support and help your child to learn important social skills.

A bit like going to primary school, moving into secondary school can be difficult for your child as there may be many new teachers and pupils who have not come across people with birthmarks before. The challenges of going to primary school may therefore be repeated.

Children may also start to become aware of romantic relationships around this time. This growing awareness may trigger more thoughts, feelings and questions about the importance of their own looks.

Some or all of the following ideas may help at this time:

- **Building friendships.** Encourage and help your child to develop close and positive friendships.
- **Promoting strengths and self-esteem.** Continue to praise and encourage your child's development of skills and talents, appreciate their efforts and achievements. This will help them to develop good self-esteem which, in turn, will assist them to deal with some of the less positive experiences of growing up.
- **Continuing support and communication.** Go on dealing with the inevitable hiccups in your child's life in a calm and sensible fashion. Be prepared to respond to more complex questions and emotions about your child's birthmark and lots of other issues as he or she matures and becomes more emotionally sophisticated.



Challenges and solutions during adolescence

How your child looks, and mixes with people of their own age, becomes increasingly important now. Another big part of adolescence is gradually loosening the bonds with family. There are also lots of other pressures on teenagers to do with physical development, school exams and thinking about the future.

In all families, there are often conflicts at this time, which may be made worse because your child has a birthmark and is struggling with their looks and mixing with their peer group. This is often a time when children with a condition affecting their appearance start to understand its full reality and how it might affect their life. For some adolescents this can be a very difficult time, while others find it liberating.

Now that your child is becoming more independent from parents and family, you will probably find that you have less influence on what they think and do. It may be a time when you find it very hard to do or say things that help them.



Some or all of the following ideas may help at this time:

- **Remembering that ups and downs are normal.** As with any teenager, be prepared for emotional fireworks, no matter how well you've prepared yourself for this stage in your child's life.
- **Supporting your teenager.** Your child will be thinking in a far more complex way than ever before and will probably have lots of complicated questions. This is an important part of becoming an adult. Be honest and admit when you don't know the answers. Let your child know that it is OK for them to talk to someone else like their GP or a support group and help them to find this support. The contact details at the end of this leaflet may be useful. You may find that it's more effective to get someone else to provide support for your teenager such as a family friend or a teacher who your teenager trusts and gets on with.
- **Getting involved.** Include your child, as much as possible, in making decisions about all aspects of their life and medical care. This helps them to feel included, respected, responsible and in control of their life. Make sure you listen to what they have to say.

What about brothers and sisters?

Siblings often feel left out and forgotten when they have a brother or sister who is different or has special needs. Sometimes, their behaviour may not seem very caring, but it is important to remember that siblings care for each other a great deal. Brothers and sisters can be just as worried about their sibling as you are about your child. Most of the suggestions above apply to siblings as well as to the child who has the birthmark. Siblings of a child who looks different need to learn how to deal with stares, questions and comments about their brother's or sister's looks.

As much as possible, coping with a family member who looks different should be a family affair. If brothers and sisters are included and informed they will feel happier and more settled and they too can become a valuable source of support.



Who else can help?

- **Your GP/paediatrician.**
This is always your first line of contact for getting more information about your child's condition and medical treatment. They can provide support, information and ongoing care themselves and can also refer you to other sources of support.
- **Community child and family clinics.**
These NHS clinics are situated in your local area and usually include a range of mental health workers such as psychologists, psychiatrists, social workers and specially trained nurses. These clinics are useful if your child has problems with their behaviour or emotions, or if there are problems within the family. Your child can be referred to the clinic nearest to you by your GP or other professional involved in their care.
- **Hospital-based psychological support.**
Many district and national hospitals employ clinical psychologists who specialise in the mental and emotional health needs of people who are ill and their families. Your hospital consultant will be able to refer you to the appropriate person.

Further information

- **The Birthmark Support Group**

This organisation is run by people personally affected by birthmarks, and helps individuals with birthmarks and their families. They provide a wide number of services including information on birthmarks, counselling and contact with other people in similar circumstances. The group also arranges meetings where issues relating to birthmarks are discussed.

Birthmark Support Group
PO Box 3932
Weymouth DT4 9YG

Email: info@birthmarksupportgroup.org.uk
Website: www.birthmarksupportgroup.org.uk

- **Changing Faces**

This professionally-staffed charity provides support to individuals and families dealing with visible differences and disfigurement. It provides a wide range of support services including phone, mail and face-to-face discussions as well as information and support to professionals involved in your child's care. They produce a number of useful resources and booklets and are a good place to start when wanting to find out more about these issues.

Changing Faces
1 & 2 Junction Mews
Paddington
London W2 1PN

Tel: 020 7706 4232
Email: info@changingfaces.co.uk
Website: www.changingfaces.co.uk



If you have any problems and would like help or advice, please contact Changing Faces on 020 7706 4323

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