

0-3 years. Guides for Parents

Guide 3. Meeting people and feeling good

If your child was born with, or acquired, a medical condition which has affected his appearance, it is likely that you are still finding out how this affects him and adjusting to this unfamiliar experience. You may still be in shock, or feel angry, sad or confused.

Going out to the shops, the park or taking your child to playgroup are everyday activities that may now bring unexpected difficulties. A stranger's friendly overtures when seeing you and your child can turn into expressions of surprise or even shock when they notice his disfigurement. People may avert their eyes, change their mind about talking to you and walk away. They may ask what happened or blurt something out rather than the more usual 'Hello'.

It might feel as if the only answer is to avoid going out. This may protect you and your child from other negative reactions but it will also deprive both of you of much needed social interaction. It is through play that children learn social rules (like taking turns, joining in and how to make friends). It is also through play that children can practise and learn new physical skills (like climbing, throwing, painting).

Interacting with others, especially other parents, is also of benefit to you. Although you may have some unique experiences, it can make a real difference to feel supported by other parents, who are also struggling with sleepless nights, relentless nappy changing and constant attention being focused on someone else.

If you have been finding it hard to cope with other people's reactions on a daily basis or you're avoiding going out with your child, this Guide offers some useful strategies and suggestions for responding to people's curiosity, forging friendships and encouraging your child to join in.

1 GOING OUT IN PUBLIC

You are standing in the queue to pay at the supermarket when you suddenly notice that someone is staring intently at your baby or nudging their companion. You are walking down the street when someone just comes right up and asks about your child's appearance. It is this sort of casual encounter that is often so difficult for parents because it is so unexpected and intrusive. Many parents report feeling completely unprepared to deal with this sort of curiosity which can leave you feeling angry, sad or anxious about going out.

More often than not, such curiosity or concern is a natural human response when we see something different or unusual for the first time. (Occasionally, people are familiar with your child's condition and are approaching you to offer a friendly word).

Try the Explain- Reassure- Distract technique

The **EXPLAIN-REASSURE-DISTRACT** technique can help you to act in a way which makes you feel more in control, can put others at ease and enable you to get on with your day. Being able to handle other people's reactions confidently will boost your self-esteem and make everyday encounters more enjoyable for you and your child.

Explain and reassure

Having a brief explanation ready when you notice someone staring at your child or if they ask a question can diffuse an awkward situation. It can help people to move beyond their initial reactions and make it easier for you to get on with your normal routine.

There is no need to provide adults or children you meet in public with in depth medical explanations. A brief and straightforward answer will satisfy most people.

EXAMPLES

- I see that you have noticed Maria's face. It is the way she was born.
- Zarina's face is swollen on one side. It doesn't hurt her.
- Mason has eczema. That is why his skin is red and itchy. You can't catch it.

Sometimes it is enough to just smile at the person. This can break a stare or reassure someone. Simply saying "hello" also lets people know that you are OK and it suggests that they can be friendly too.

Distract

You don't have to continue talking about your child's visible difference. You can move the conversation on to something else or end it politely so that you can get on with your day.

EXAMPLES

- We don't mind talking about Aiden's Aperts but we do need to get going now.
- Max has a big eye and a small eye. His eyes are brown. What colour are your eyes?

2 MEETING NEW PEOPLE IN THE PARK

When you take your child to the park, you will meet other parents and children who live locally and who you will see on a more regular basis. In this type of situation where you may want to make friends with the other parents or encourage your toddler to play alongside other children, it helps to expand your explanations in response to any initial curiosity.

Also, bear in mind some of the other things that people might be thinking about your child – is his skin condition contagious or can she grip the climbing frame? They may assume that a child who has a visible difference must need extra help or have delays in talking or development.

Although some children may need extra support or have learning difficulties, this is not always the case so by expanding the **EXPLAIN – REASSURE – DISTRACT** technique you can reassure people and clear up any misconceptions.

EXAMPLES

- Sam's legs get more tired than other children and that's why he uses the buggy.
- Billy was born with a tongue and body that are bigger than other children his age but he likes playing at the park just like you.
- Dillon's hands look different to yours. It is the way he was born. Do you want to

- play with the ball?
- Setsuko has a brown birthmark, like a mole. Do you have any moles or birthmarks?

Some of these explanations may seem too complicated for a young child to grasp but even if the explanation seems too advanced, it is the tone, friendliness and reassurance in the message that is just as important as anything else. Plus, local children will become familiar with the words and will, over time, come to understand both the meaning of the words as well as the intention.

3 GOING TO PLAYGROUP

Going along to a coffee morning, a mother and baby group, story time at the library or to a playgroup is an excellent opportunity for you to meet and share your experiences of being a new mum or dad with other parents, whilst your child plays and interacts with other children. Socialising, especially for the younger child, is particularly important as they will pick up new skills, acquire a better understanding of their environment, and learn about themselves and other people. You will also be able to recharge your batteries, while your child is busy playing!

Prepare yourself

Preparation is one of the best ways to help you overcome your fears and enable you to handle any situation that may arise.

- Think about some of the situations that you might come across during the day - it might be people's comments, no one wanting to speak to you or other children refusing to play with your child. Think about what you can say or do if this happens. If you really feel uncomfortable, what can you do to look after yourself and your child?
- Think about what you would like to gain from this experience and what you can do to achieve this. If you want to make friends or help your child to join in, you will need to introduce yourselves and take steps to encourage this.

At first it can be helpful to go along with someone you know will support and help you out like a friend, a sister or your own Mum. You could chat to the leader if it is an organised group and explain your concerns and ask for some introductions. Perhaps you can prepare some small talk to rely on in these situations (e.g. do you live around here, do you have any other children, how long have you been coming to the group?). Remember if it feels difficult, talk to the friend or relative you have brought with you.

Use the Explain-Reassure-Distract technique

Explain

It is helpful to come up with at least one explanation that everyone caring for your child (relatives, friends, other parents, nursery or playgroup staff, child minder etc) can use about his disfigurement. Hearing this explanation helps your child to become familiar and confident about his condition and will teach him that it is nothing to shy away from.

EXAMPLES

- One of Jessica's ears is smaller than the other. She doesn't hear so well with her little ear but the other ear works just fine.
- That is Danny's scar. He was born with a cleft. The doctors have fixed it.

Reassure

You may also want to include explanations about how this affects your child. For example you could say:

EXAMPLES

- Maria's face looks different but her development is just like any other child her age.
- Bob looks different because he has Crouzons. He had to spend a lot of time in hospital when he was little. He isn't talking yet but he understands what you are saying and loves to play.

Distract

You don't have to continue talking about your child's condition. You can move the conversation on in a natural and appropriate way. At playgroup or a parents group it is easy to focus on things you may have in common or to engage in small talk.

EXAMPLES

- What is your son's name?
- Do you live near by?
- I got very little sleep last night. Marla is teething.
- I wondered if you knew of any good child minders? I am going back to work soon.

4 HELPING YOUR CHILD TO JOIN IN

Children of this age often need encouragement in playing together. They may have some of the skills (e.g. sharing, turn taking) but they will not remember to do it all the time. It is helpful to suggest how your child can join in rather than insisting that he plays with others.

Your child will hear the simple explanations you are using to describe his condition. He will also be watching what you say and do at the park or at playgroup. If you can model the following skills for meeting people, joining in and making friends for your child, he will feel more confident about trying them out for himself.

- Greeting people by name with eye contact
- Introducing your child to others
- Smiling more and making eye contact
- Asking to join in a game that others are already playing
- Asking someone else if they would like to join in with what you are doing
- Suggesting a game or activity
- Starting a new conversation, or changing the subject with a question.

These skills will also be helpful for siblings who may find social situations tricky as a result of reactions to their brother or sister's appearance.

Ibrahim, 2 ½ years old, is at playgroup with his Mum. He is staring eagerly at the playdough but is not joining in.

Mum says, "Who is playing with the playdough today?" She waits to see if he will answer. When he doesn't she says, "Isn't that Timmy and Beltan? Come, you can join in."

They make their way to the table but Ibrahim clings to his Mum's dress. "Here is a chair for you Ibrahim. Hello Timmy. Hello Beltan. Can you pass Ibrahim some playdough please? Thank you." Ibrahim picks up the playdough and finds a shape cutter and starts playing.

Mum steps back and lets him play. She watches what goes on while she has a cup of tea.

5 MANAGING RUDENESS

Some people are rude, have made assumptions or don't know how to respond appropriately to a difference in appearance. Being assertive - stating what you feel and want without getting angry or abusive can be a very empowering way of dealing with this.

WHAT TO SAY IF SOMEONE IS RUDE ABOUT YOUR CHILD'S APPEARANCE

- "My son's face is asymmetrical. It is the way he was born. We don't like it when people stare. We would prefer you to say hello or ask us a question if you are curious."
- "My child just has a scar. It happened a long time ago. There is no need to be rude."
- "My child has Nf. He may look different but he can hear and what you said really hurts."

6 YOU DON'T HAVE TO EXPLAIN ALL THE TIME

The suggestions above may feel hard to put into practice but parents often remark that the more they use the strategies, the more confident they feel and the more they enjoy going out. Sometimes, just thinking through your options with someone close to you and coming up with some ways to handle situations can help you to feel more in control and able to just enjoy spending time with your child.

Look after yourself

However, you are not expected to find a way to manage every situation. Take it one step at a time. Some days will be better than other days. On good days you may feel like going to the park or shops and be confident in responding to other people. If you have a day when you have found other people's reactions difficult, you may like to do something to calm down or relax e.g. go for a cup of coffee, invite a close friend around or just have a cry on your partner's / friend's shoulder.

Positive self-talk

Some times you will have to go out, even if it is not a good day. If you don't want to explain or you need a confidence boost, try having something to say to yourself that will reassure you.

This might seem strange but evidence shows that the more we think and act positively, the more we are likely to feel positive. One of the ways to challenge negative thoughts is through positive self-talk, and the more we do it, the more our brains will start to do this on their own. So, the perfectly natural thought of "I can't cope anymore!" is challenged by acknowledging the ways that you have coped before, and planning how you will cope next time. Here are some more examples:

- "I will be OK."
- "We have done this before and we can do it again today."
- "These are my children and I'm proud of them."
- "I will ignore those who stare. I will smile and show them that I am OK."

7 SIBLINGS

When a child has a disfigurement, it affects everyone in the family to some degree. Most siblings cope well when they are supported to understand and accept their brother or sister's difference.

However, they may feel left out when their brother goes to hospital or they may get teased or asked questions about their sister's appearance. It is therefore helpful if siblings can also learn ways of joining in and explaining their brother or sister's difference.

Teach them the **EXPLAIN-REASSURE-DISTRACT** technique:

- This is my sister. She's got a birthmark. Do you want to play with us?
- David is my younger brother. He has one small ear. Do you have a brother too?

It is also important to include siblings in discussions about their brother's visible difference (see the *Changing Faces*' Guide on *Talking to Children about Disfigurement*) and to set aside time for them to share their feelings and concerns.

8 I'M FINDING IT DIFFICULT

As the parent of a child with a visible difference, there are so many things that can feel strange and overwhelming. At this point in time, you may have other priorities - your child may just have been diagnosed or may still be receiving treatment – or everything might just feel very busy. If this is the case why don't you put this leaflet down and return to it when it suits you? Focus on what is important right now, give yourself some space and time, and make sure you take care of yourself.

Many parents find it helpful and reassuring to talk to someone who understands the unique situation they are in. It can be liberating to be able to express your feelings openly either on your own or with a partner about having a child who looks different.

You can contact *Changing Faces* on 0845 4500 275 or email info@changingfaces.org.uk for professional support, information and advice. *Changing Faces* can also put you in touch with other organisations and support services which might be useful at this time.

9 OTHER HELPFUL ORGANISATIONS

Contact a Family 209-211 City Road, London EC1V 1JN. 0808 808 3555
www.cafamily.org.uk

Gingerbread First Floor, 7 Sovereign Close, London E1W 2HW Tel: 0800 018 4318
Helpline (Mon-Fri, 10am-4pm) e-mail: office@gingerbread.org.uk Web:
<http://www.gingerbread.org.uk> *Puts you in touch with local support groups for lone parents.*

National Childbirth Trust Alexandra House, Oldham Terrace, London W3 6NH 0870 444 8707 www.nct.org.uk *Charity for pregnancy, birth and parenting in the UK. local branches run by volunteers offering services, activities and opportunities for new parents to meet other parents.*

Parentline Plus Helpline 0808 800 2222 Textphone - 0800 783 6783
www.parentlineplus.org.uk *Offers helpline and support to parents. Run workshops to give parents tools and ideas to build closer relationships with their children and to help their children to make the most of life. Secure and confidential email support via website.*

Working Families 1-3 Berry Street, London EC1V 0AA Tel: (020) 7253 7243 Legal
Helpline: 0800 013 0313 e-mail: office@workingfamilies.org.uk Web:
<http://www.workingfamilies.org.uk> *Offers information and advice to working parents and has an established network for parents of disabled children.*