

Introduction to *Changing Faces*' Guides for Parents

Being the parent of a child who has a condition which affects her appearance - e.g. cleft lip and palate, Aperts or Goldenhar Syndrome, birthmarks, scarring from cancer treatment, burns or an accident, or a skin condition - can often feel like being an explorer in a new land. People use unfamiliar words and behave in unusual ways; there are lots of conflicting emotions; you may be unsure which way to turn and just when you think you're out of one wood, there can be another forest obstructing your path.

Knowing what to do or say and how to handle the many different situations you may come across can make a big difference to the confidence levels of your whole family and help you to feel positive about the future.

Changing Faces' Guides for Parents aim to equip you with some straightforward, very practical skills and tools to overcome some of the most common challenges and uncertainties that parents face. These include:

- Managing the first weeks and months after your baby is born
- Finding out about your child's condition and coping with medical treatment
- Learning how to talk about your child's visible difference
- Handling other people's reactions to your child's appearance
- Preparing for playschool, nursery and junior school
- Helping your child to make friends and join in.

We recognise that families approach things in different ways and medical conditions affect children in many different ways. The Guides also contain information about finding further support for yourself and for your child.

LANGUAGE AND STYLE

The word 'disfigurement' is used in these Guides as a semi-neutral word to describe the aesthetic effects of a mark, scar asymmetry or paralysis to the face or body. *Changing Faces* only uses the word as a noun e.g. "a child who has a disfigurement." It never refers to "a disfigured child."

We recognise that the word 'disfigurement' is not particularly positive and some parents may not want to use it to describe their child's condition or appearance, preferring other words like 'visible difference', 'unusual appearance' or the name of their child's condition. These words also appear in the guides.

For the time being, the charity continues to use the word 'disfigurement' as it is easily understood and particularly as the term is enshrined in British law in the Disability Discrimination Act (DDA) 1995 which protects children and adults who have disfigurements.

The Guides also alternate between the male and female gender when referring to the child with a disfigurement. This has been done to demonstrate equality and is in no way discriminating. All ideas apply to girls and boys.

HOW TO USE THESE GUIDES

There are 10 Guides in the series. Each Guide focuses on building your skills at different stage of your child's development between birth and 11 years of age.

Newborn – 3 years		3 - 6 years of age		7 -11 years	
1	When your baby looks different	1	Talking to young children about disfigurement	1	Talking to older children about disfigurement
2	Going into hospital	2	Going into hospital	2	Going into hospital
3	Meeting people and feeling good	3	Meeting people and joining in	3	Making friends and fitting in
4	Finding further support	4	Finding further support	4	Finding further support

Newborn – 3 years

A child develops tremendously over this time from total dependence on you to walking, talking, exploring, feeding herself, playing.

- *When a baby looks different* acknowledges some of the feelings you may have at this time and provides some gentle advice on handling some of the unfamiliar situations you may find yourself in. There are some ideas on introducing your baby to family and friends and suggestions on how you can talk to your baby about her difference.
- Making decisions about medical treatment, watching your child undergo surgery and taking care of her afterwards present some of the biggest challenges for parents. *Going into hospital* focuses on helping you to support your child and yourself during these times.
- New parents often find handling other people's reactions to their child very hard. *Meeting others and feeling good* takes you through different social situations step-by-step and includes lots of examples of things you can do and say so that you feel more confident and in control.

3-6 years

Children are naturally curious at this age and will be aware of differences around them. Your child will also be aware of how you are talking about her disfigurement and how you respond to other people's curiosity. She will also be starting school and socialising with other children.

- *Talking to young children about disfigurement* explains why it is important for children to hear their visible difference talked about in a straightforward, everyday way and gives you ideas about words you can use as well as how and when to bring up the subject.
- Your child will be more aware of what is going on around her and *Going into hospital* looks at how you can prepare your child for going into hospital and allay her fears. This guide is also suitable for children between 7-11 years.
- *Meeting others and joining in* explains how to handle other people's reactions to your child's appearance and encourage her to join in and play with other children.

It also provides a useful introduction to supporting your child when she starts school.

7-11 years

Your child will be at school or doing lots of activities without you so the Guides in this age group help you and your child to feel confident and prepared for this new-found independence.

- *Talking to older children about disfigurement* explains how to develop and adapt the ways you talk about her visible difference to suit various situations.
- *Going into hospital* shows you how to involve your child in her medical treatment whilst providing her with the reassurance she still needs.
- *Making friends and fitting in* acknowledges the importance of feeling that you fit in for this age-group, particularly at school. It shows you how to role-model approaches to various situations and how to encourage your child to use them herself.

After reading the Guides, you might like to find out about further support for yourself or your child. The Guide called *Finding Further Support* can help you to do this.

The Guides acknowledge that children develop at different rates and have different needs so don't worry if you feel you or your child aren't ready for some of the suggestions. You might find it easier to start with one Guide rather than reading through every Guide in a particular age-group – whatever feels right for you.

If you would like some advice on choosing a Guide, please contact the Children and Young People's Service at *Changing Faces* on 0845 4500 275 or email changingfaces.org.uk. You can also download the Guides from *Changing Faces'* website at www.changingfaces.org.uk.

ACKNOWLEDGEMENTS

A number of the Guides for Parents refer to a technique called the Explain-Reassure-Distract technique which is particularly useful when handling other people's reactions or meeting people for the first time. This technique has been adapted from REACH OUT, *Changing Faces'* core strategy for communicating with other people, which was devised by James Partridge, Founder and Chief Executive of *Changing Faces* in 1995.