

Guides for Parents

Finding Further Support

As the parent of a child who has a disfigurement, you may find that you need extra support and advice or information at different times. Seeking support can be as simple as talking to someone and having your feelings acknowledged about your child's appearance. Alternatively, you may want to find out more about her condition, particularly if it is rare. Your child might be starting school soon and you want to make sure that she feels accepted and can make friends. You may even want to offer support to other parents in similar situations.

This Guide directs you to the organisations and services available to you and suggests how best to use them.

1 FINDING EMOTIONAL SUPPORT

Bringing up a child who has a disfigurement can trigger off many different emotions at different times. If you are feeling overwhelmed by your feelings or you are constantly anxious, you may want to seek professional emotional support.

It can be liberating to have a place to express these feelings openly either on your own or with a partner. Please remember that seeking support is not a sign of weakness or failure. Being able to acknowledge your feelings and talk about what has happened can help you and your child rather than acting as a sign of deeper psychological problems.

Changing Faces

The Children and Young People's Service has 14 years' experience of providing professional support to children who have disfigurements and their parents. Emotional and practical support is available by phone, letter and email and the charity also offers telephone or face-to-face counselling for parents and children.

For further information about the support offered by the Children and Young People's Service at *Changing Faces*, please contact 0845 4500 275 or email info@changingfaces.org.uk.

Via your GP

For a referral to a psychologist or counsellor in your area, please contact your GP. It helps to clearly outline how you are feeling, how long you have felt this way, what your concerns are and to share any specific difficulties you are having (e.g. crying every time you think of your child's birth or fearful for your child's future).

You may have to wait some time for a referral and you may find it helpful to speak to a specialist at *Changing Faces* in the interim period.

Via the specialist team looking after your child

In some instances there are psychologists dedicated to the medical or surgical department (e.g. the Neurology department, Dermatology department or Cleft Team) responsible for your child's care. This support is for you as well as your child. Share your concerns and any specific difficulties you are having with a member of your child's team who you feel comfortable with (e.g. consultant, nurse specialist, speech therapist). If the person you speak to cannot make a referral themselves they will be able to tell you how to go about getting a referral.

Other Useful Organisations

British Association for Counselling and Psychotherapy, Tel: 0870 443 5252 e-mail: bacp@bacp.co.uk Web: <http://www.bacp.co.uk>

This organisation can provide you with a list of counsellors in your local area who you can contact directly.

2 MEETING OTHERS IN SIMILAR SITUATION

Professional support can be very useful but you may just want to know that you are not alone. Some parents have found it very helpful to meet other families with a child with the same or similar condition to find out about what to expect and how others have coped.

***Changing Faces'* Exchanger Scheme**

Changing Faces runs an Exchanger Scheme which puts parents in touch with one another to share experiences and ideas for managing different situations. Although we cannot promise to put you in touch with a family whose child has exactly the same condition, we might be able to put you in touch with a family whose child has a similar condition or where the parents have had a similar experience.

For further details about *Changing Faces'* Exchanger Scheme please call 0845 4500 275 or email info@changingfaces.org.uk.

Joining a support group

Some support groups set up family conferences where you can meet other families. Others put families in touch with one another. Some parents specifically want to talk to other parents who have a positive outlook and can show how they have coped with difficulties and help them anticipate things that may happen in the future.

Before you meet another family through a support group, it can help to think about what you want from meeting them - friendship, positive models of coping, shared experiences (good and bad), information regarding unusual treatment options. Share these expectations with the support group leader so that they can put you in touch with a family whose outlook is similar to your own.

Changing Faces holds a list of support groups which is available on our website at www.changingfaces.org.uk. Alternatively, call 0845 4500 275 or email info@changingfaces.org.uk for further details.

Contact A Family

This is an organisation that has a directory of support groups and up-to-date information on conditions. They provide information regarding disabilities and special needs, including information on benefits, and caring for a child with multiple and complex needs. They also hold details of families with extremely rare conditions who are willing to be in contact with other families.

Contact a Family also has regional offices that offer a range of support to families from workshops on 'Coping with Challenging Behaviour' to social events so that parents and children can meet each other.

Call 0808 808 3555 or visit www.cafamily.org.uk for further information.

Speak to your child's nurse specialist or play specialist

A lot of parents have got in touch with each other by meeting in hospital. Chat to your nurse specialist or play specialist. They may know of another family you could contact.

Local groups

Contact your local council to find a list of local support groups or carers groups. You may not consider your child's condition to be a disability but if they are receiving ongoing medical treatment or have special needs it is likely that you share a lot in common with parents who have a child with a disability.

2 FINDING OUT ABOUT MEDICAL CONDITION AND TREATMENT

Getting accurate information about your child's condition and its treatment or management can help you to feel less anxious and helpless.

Your child's Consultant, GP or nurse specialist

The health professionals caring for your child are often the first people to tell you about your child's condition. Don't be afraid to ask the doctor or other health professional for written information about your child's condition but do be aware that this is not available for every condition. Some departments also have nurse specialists who can answer your questions and provide further information.

Changing Faces

Changing Faces can direct you to services to find out more about a condition and its medical treatment as well as suggesting some questions you could put to specialists. We cannot give answers to condition specific medical enquiries or recommend particular treatments or practitioners.

We are also in touch with a broad range of support groups representing many different conditions. Many of these groups have up-to-date and extensive information about a medical condition and the treatments available.

Using the Internet

If you want to use the Internet to find out more about your child's condition and treatment options, we advise you to access evaluated subject gateways which provide high quality health information. It is especially important with medical information that the website providers ensure that any material is accurate, relevant and up-to-date.

Medical conditions affect children in different ways so it is important and extremely helpful to pass on the information you gather to the health professional (e.g. consultant or nurse specialist) caring for your child so that you can discuss how it relates to him in particular.

For further information on conditions and advice on gathering medical information via the Internet visit the following websites:

Contact a Family

www.cafamily.org.uk/info.html

Great Ormond Street Hospital for Sick Children

www.gosh.nhs.uk/gosh_families/health_advice/health_info_online.html

Judge: 'Websites for Health' Project

www.judgehealth.org.uk

3 FINDING SUPPORT WHEN YOUR CHILD HAS MEDICAL NEEDS, SPECIAL NEEDS, OR LEARNING DIFFICULTIES

When a child has a condition that affects their appearance, it can impact on the child and parents in a variety of ways. Some children will have a physical disability or learning difficulties, need extra support at school due to a specific difficulty or need extra care.

If you are concerned that your child may have a particular difficulty (e.g. has not learnt to speak, is struggling to write compared to others his age, has behaviour that is difficult for you and others to manage) then speak to his consultant, GP, paediatrician, teacher or the school's Special Educational Needs Co-ordinator (SENCO). They can then refer you if your child needs further support or assessment.

Social Services

Your local Social Services Department may also be able to help if your child is disabled and/or you spend a lot of time caring for him as a result of his medical needs. Contact your local Social Services Department or visit www.disability.gov.uk.

Changing Faces' Work in Schools

Our School Specialist can help if you are concerned about how your child's appearance and related disability, medical or special needs could affect their time in school. You might find it useful to contact us before your child starts school or nursery or when he is moving on to a different school so that we can help you prepare effectively or liaise directly with the school or nursery on your behalf.

Changing Faces can also put you in touch with other organisations and education support services in your area.

4 CHANGING FACES' RESOURCES

Self Help Booklets for Parents

My Child Looks Different

Provides information and advice on handling common situations that many parents come across when their child has a disfigurement.

Exploring Faces Through Fiction

Explains how parents can use stories to help their child talk about his face.

My Child Has Burns

Provides information and advice for parents whose children have burns.

Talking to Health Professionals

Talking to health professionals can leave many parents feeling frustrated. This booklet explains how to communicate effectively with health professionals.

Teachers' Guides

These Guides are for teachers and others who work with children and young people, usually but not always in schools.

Each age-linked Guide contains twelve sections which cover the particular issues teachers face when they have a child with a disfigurement in their class. Each section provides information based on research findings, practical advice and suggestions for lesson plans.

If your child is going to nursery or school, you might like to suggest that your child's school contacts *Changing Faces* to order the Guide for the relevant age group.

Self Help Booklets for Children

Looking Different, Feeling Good

What Happened to You?

Do Looks Count?

You're in Charge!

Four booklets which can be ordered as a set or individually which reflect the experiences of children aged 10 years and over who have a disfigurement. The booklets show children how to find out more about their condition and prepare answers to comments and questions; how to feel positive about the way they look; and how to come up with strategies for handling other people's reactions and awkward situations.

Fiction

Show Time!

A simple, beautifully illustrated story for younger children about a child who has a disfigurement.

Humpty Dumpty Faces the Future

Turns the traditional Humpty Dumpty story on its head. For all age groups from 9- 90 yrs.