

You and your child

Parent guides



**CHANGING
FACES**

This guide aims to:

- **Look at the meaning of ‘visible difference’ or ‘unusual appearance’**
- **Explore some of the challenges for you socially**
- **Look at your needs and challenges as a family**
- **Provide you with a range of techniques, resources and information**

Contents

Part 1	
What do we mean by 'unusual appearance?'	4
Your child is not alone – facts and figures	5
Meeting the challenges	6
Five helpful techniques	7
Unwanted attention	9
Meeting new people	16
Finding out about your child's condition	19
Part 2	
Looking after yourself	21
Feelings of loss	22
Low self-esteem	23
Siblings	25
Staying positive	25
Take it at your own pace	27
Summary	28

What do we mean by unusual appearance?

'Unusual appearance' is just one of the terms Changing Faces uses when referring to the effect of any trauma, medical condition or treatment on the appearance of a face or body. This may mean that your child:

- Looks different or unusual
- Has scarring
- Looks asymmetrical
- Has a part of their face/body that does not work in exactly the way it did or should

Changing Faces also uses the terms 'condition', 'looking different' and 'disfigurement', when appropriate. 'Disfigurement' is used in the [UK's Equality Act 2010](#) to protect people from discrimination. However, we recognise that disfigurement is not a term preferred by many people who are affected. Many parents prefer, when describing their child's condition, to name the condition, by saying: "my child has a birthmark" or "s/he has neurofibromatosis" or similar. Anyone can be affected by a disfigurement or an unusual appearance – at any time, at any age, from any background. You, or someone you know, may have been born with a condition. Or perhaps this was caused later, by an accident, an illness or from an injury due to a violent act or self-harm.

Only you, and your child if old enough, can judge the impact of their condition. Your child's difference may be very visible to others, or, what some people call 'minor'. Your child's condition may be visible on their face, or on their hands, or hidden by clothing on their body. Understandably, any type of unusual appearance may be important to your child – and may cause them to feel upset, anxious, embarrassed or unconfident.

Your child is not alone – facts and figures

Over 1.3 million people have a disfigurement to their face or body in the UK – that's one in 45.

Around 540,000 people have a facial disfigurement – one in 111. Of these:

- 92,000 have congenital/birth conditions like birthmarks, cleft lips/palates
- 66,000 from accidents such as burns and facial scars
- 40,000 from cancer-related disfigurements, from surgery for skin cancer
- 25,000 have disfigurements to or around the eye
- 100,000 have facial paralysis including from stroke
- 220,000 have skin conditions like psoriasis, vitiligo and acne

In a year, 415,000 people in the UK are born with or acquire a disfiguring condition to their face, hands or body.

Meeting the challenges

“As well as living with this syndrome, coming from an intimate small nuclear family and huge extended family, and have always had amazing friends, always been surrounded by love, I lived with extreme sadness. How can someone surrounded by so much love have felt so sad and isolated? Because I was the only person I knew with a facial disfigurement, in my school, within my place of worship, within my huge Italian family, out of all of my friends, I was the only one.”

Nadia

Looking different can be very challenging for your child and family as a whole. However, although it can take time, evidence shows that many people manage to cope successfully.

Some of the specific challenges are explored in more detail, with suggestions on how you might be able to manage these situations, including using the five helpful techniques described below

EXPLAIN – REASSURE – DISTRACT – ASSERT – HUMOUR.

Five helpful techniques

Changing Faces has identified these five simple techniques:

EXPLAIN – REASSURE – DISTRACT – ASSERT – HUMOUR

They may sound too simple – and clearly some situations can be a lot more complicated. But, remembering the five techniques can be a quick and easy prompt when you are in a challenging situation – reminding you of some ways to cope. Of course, each person will be different.

Depending on the situation and your experiences, you can try them out and decide what works best for you, your child, and when to use it. The techniques can be used for you, your child and in your communication with other people.

TECHNIQUES	Yourself	People you meet
EXPLAIN	Explain to yourself why something may happen, e.g.: if a person asks a question about your child's condition, tell yourself, <i>"This person is curious about my child"</i> or <i>"He has not seen my child's condition before".</i>	Explain your child's condition to the other person, to help them understand, e.g.: <i>"It's just a scar"</i> , <i>"Mary has something called vitiligo"</i> or <i>"Mary's face is different, but she is just the same as anyone else."</i>
REASSURE	Reassure yourself, e.g.: <i>"I am ok."</i> or <i>"This person does not mean to ignore me – they are looking away because they don't know what to say."</i>	Reassure the other person, e.g.: <i>"It doesn't hurt"</i> , <i>"She is fine with it"</i> or <i>"It's ok, she's had it all her life."</i>
DISTRACT	Distract yourself in a difficult situation by thinking about something else, e.g. count to 100, say the alphabet backwards or think about something that makes you feel good.	Distract the other person by talking about something else, e.g. <i>"The food here is great, isn't it"</i> or <i>"Who do you know here?"</i>
ASSERT	Assert yourself by showing you are in control – either walk away or make a short statement, e.g. <i>"Please stop staring at my child."</i> or <i>"I didn't ask for your opinion."</i>	The other person is most likely to be embarrassed or surprised. Even if they are not, walking away shows you are in control.
HUMOUR	Use your sense of humour to either lighten the situation or put the other person in their place, e.g. <i>"You seem to find my child very interesting."</i> or	The other person may laugh or respond in light of the humour... or be embarrassed.

	when someone makes an obvious statement respond by saying: <i>“Wow – nobody’s ever pointed that out before!”</i>	
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There is a lot more information on social and communication skills in our other parent guides - [Communicating with confidence](#), [Talking with your child](#), [You and your child](#), [Preparing for school](#) and [Preparing for hospital](#).

Unwanted Attention

The challenge

Many parents find that one of the biggest challenges for them and their child is the unwanted attention they receive. This may be staring, double-takes, comments and even unkindness.

A couple of examples might be:

- 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
or
- You are walking down the street when someone just comes right up and asks about your child's appearance.

Understandably, this attention can be upsetting and intrusive and is often difficult for parents because it is so unexpected. Many parents report feeling completely unprepared to deal with this sort of curiosity and it can leave them feeling angry, sad and anxious about going out.

Mostly this behaviour is thoughtless; many people are just curious and don't mean to upset you – they forget to think about how you and your child might feel. 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 might be familiar with your child's condition and are approaching you to offer a friendly word.

Unfortunately, there are some people who stare excessively, laugh or say something rude – and a few will be very unkind. Some people may move away, look away or ignore you.

As a parent, dealing with this day in day out can be difficult and may mean you often feel:

- Judged or criticised by others
- Embarrassed and ashamed
- Anxious and panicky
- Angry and defensive
- Different and noticeable
- Cut off from other people
- Sad and depressed

- Worried and scared
- Unconfident

You may get to the stage where you assume you will be treated this way by every one - and you may end up expecting to always feel bad when you go out in public with your child.

It's understandable you may want to avoid uncomfortable or difficult situations. You might think it's unfair you have to make all the effort. However, avoiding going out is likely to limit both you and your child's life. You may become very anxious about it, making it even harder for you to face social situations.

Managing it

Understanding why:

- Technique used = **EXPLAIN** – **REASSURE**

It can help to try to understand why people stare – and this will help you to explain the staring to yourself. Not everyone will have met someone with your child's condition before – and most of us are naturally curious when we see something or someone different. People often look longer than usual without realising they are doing this, to make sense of what they are seeing. People might stare or double-take, or turn away because they are surprised, uncomfortable or unsure how to act.

Most people are not being 'deliberately' hurtful. Remembering this may reassure you. Maybe you could think of a time you were interested, shocked or surprised by someone's different appearance – it's possible you were also curious and looked for longer than usual.

SCARED

At Changing Faces, we use the word '**SCARED**' to describe how other people think and how this might make them act. It shows a range of feelings that you and your child and other people might have – and how this might make you act – creating a very difficult and uneasy situation for all to handle.

How do other people you and your child meet feel?

If SOMEONE FEELS...	→	THEY MIGHT...
Sorry / Shocked	S	Stare/ be speechless

Curious / Confused	C	be Clumsy
Anxious	A	Ask questions / be awkward
Repelled – put off by the way your child looks	R	Recoil/ be rude
Embarrassed	E	be Evasive
Distressed	D	be Distracted

How do you feel as a parent?

Being SCARED can also explain how you feel...and how you then might act in situations.

IF YOU FEEL...	→	YOU MIGHT BE...
Self-conscious	S	Shy
Conspicuous	C	Cowardly
Angry / Anxious	A	Aggressive
Rejected	R	Retreating
Embarrassed	E	Evasive
Different	D	Defensive

What happens next?

As being SCARED can create such a difficult situation, it's natural for you and the other person try to avoid each other or turn away from the conversation. As a parent of a child with an unusual appearance, you may find you contend with this over and over – as a result, you may start to stay away from social situations altogether.

This is understandable – it solves the immediate problem. However, it means you are reducing the chances of you and your child meeting people and making new friends.

We all learn by putting ourselves in new and, sometimes, challenging situations. And, sometimes, to develop new skills, we have to take a risk and make ourselves face something we have been avoiding. Tackling social situations may seem hard – but, this can be improved by learning some techniques and then trying them out, step by step. Changing Faces can [support you](#) and your child.

“Dealing with stargers...myself and a friend were going home from school on the bus and there was a guy from another school who kept staring in our direction. To make him aware that I had noticed, I said to my friend that when this guy gets off we should wave and smile at him... which we duly did. I thought it was a good way of being friendly whilst hopefully giving him something to think about.” Mark

Be prepared

- Technique used = **EXPLAIN** – **REASSURE** – **DISTRACT**

You can't stop how other people act, but by preparing in advance, you can anticipate some people's reactions and manage the way this affects you more positively, using the techniques. It will take a bit of time to find out what works for you – try different approaches out, see how successful they are and adjust next time if necessary.

Think of things you might say to yourself to explain other people's behaviour. And find something to give you more confidence and reassure you. This could be a short phrase or motto, for example:

"I am fine"

"My child looks different and that's ok"

"There is more to my child than how she looks"

You might like to think of some distractions in advance too. For example:

- Think about something or someone you like – something to make you feel happy or that makes you smile

Prepare before you go out or go to an event. Think about the situation beforehand. How might people behave? How might you respond? Think about how you will act, what you might say, how you might say it and your body language.

You will find more information about handling other people's reactions in **Communicating with confidence.**

Preparing in advance will help you feel in control and more confident – and you will probably find that people will respond more positively to you too.

What can I say?

- Techniques used = **EXPLAIN** – **REASSURE** – **DISTRACT** – **ASSERT** – **HUMOUR**

You might want to prepare a variety of responses. You can then judge when to use these, depending on the situation and your mood that day.

For instance, if people ask the question, "What happened to your child?"

1. You might decide to say, *"I'd rather not talk about it. I'm sure you can understand."* This is perfectly reasonable and a short, firm reply is fine.
2. Or, you might choose to offer a brief, simple response and then distract them by moving onto another subject. For example *"It's just a birthmark. I like your shirt – can you tell me where you got it?"* This also distracts the person from asking about your child.
3. You may give a more in-depth reply and invite further discussion. For example, *"It's just a birthmark. She's had it all her life. It doesn't cause her any problems although she has to take extra care in the sun."*

When people stare, you could try the following:

1. Look back, smile and hold the other person's gaze briefly. Most people will smile back and then look away.
2. For more persistent 'stares', look back and hold the person's gaze whilst raising your eyebrows as an acknowledgement that you've noticed their staring.
3. Ask, *"Can I help you? Do I know you from somewhere?"* This will potentially deter the observer from continuing to look and make them aware of their behaviour.
4. Or you could use humour, *"You seem to find my child fascinating!"*
5. If the person continues to look, you could try being assertive, *"Can you please stop staring at my child? It's very rude."*

Be assertive and use humour

- Techniques used = **EXPLAIN** – **REASSURE** – **DISTRACT** – **ASSERT** – **HUMOUR**

Using assertiveness and humour will very much depend on your mood and the situation. These can be used more lightly, as in the examples above. Or, assertiveness and humour can be very handy on the rare occasions you may need to deal with unkind comments.

1. Sometimes, it may be best just to walk away, particularly if you feel threatened or concerned. This is still a way of asserting yourself, by showing the person you are in control and have

decided not to respond to them. (This might leave you feeling very upset or angry – try talking to a friend or someone you trust to get support and to help you feel better.)

2. At other times, you may feel strong and safe enough to respond with an assertive reply that disarms the person. You might say:

“Do you enjoy being rude to other people?”

“I don’t like the comment you just made”

“I heard your comment and it wasn’t nice”

3. Or, you can use sarcasm and humour:

“Is that the best you’ve got?”

“Wow, how long did it take you to think up?”

“Hilarious – I’ve never heard that one before!”

“My son had an accident. Funny, huh.”

“I just happen to have a birthmark”: “I went for a browse round the local shopping centre after work and became aware that I was being followed. I managed to round up on the person following me – I then asked very loudly if there was something I could help them with – or were they a store detective? The lady concerned said, “Ooh my daughter wants to know what is wrong with you!”

I said, “I just happen to have a birthmark and would suggest in future that if you see someone that looks a little different you are not quite as rude as you have been with me, as sometimes situations like this can be stressful, and also if your daughter wants to know, then your daughter should ask me. If you want to know what is wrong with people then your best approach is to ask them directly”.” **Linda**

It is perfectly acceptable to use these options, and they can be especially helpful if you feel no others are available. These responses can show up or embarrass the other person. Like Linda, you need to be feeling confident and in control. It is important to keep control of your own feelings and try not to be aggressive, angry or unreasonable to the person. This will help you to feel in charge of the situation and will keep you safe.

3-2-1 Go!

As a simple, quick way to get you started dealing with unwanted attention:

3 things to do if someone stares at your child

- Look back and smile.
- Look back, smile and say, “I’m sorry, do we know one another” if staring persists.
- Ask them not stare.

2 things to say if someone asks what happened

- “My child has a skin condition but I’d rather not talk about it.”
- “My son’s had psoriasis for a few years but it’s not contagious.”

1 thing to think if someone turns away

- “It’s okay, they didn’t mean any harm”

For more ways to practice managing unwanted attention see [Communicating with Confidence.](#)

Meeting new people

The challenge

Going out to the shops, the park or taking your child to school are everyday activities that may now bring unexpected difficulties. A stranger's friendly approaches when seeing you and your child can turn into expressions of surprise or even shock when they notice her 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'.

Some people may make false assumptions about your child, based on her appearance. This can be hard. They may assume that your child is less intelligent, will not be successful, or that she won't have a relationship or enjoy life.

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.

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 then [Communicating with confidence](#) offers some useful techniques and tips for responding to people's curiosity and dealing with rudeness.

“I am proud of the person I am...”: “I normally am quite able to cope with reactions and stares. I recently started doing a photography course. The tutor showed us how to hold the camera correctly, with the left hand, which for me is very difficult, as I have arthritis in both hands and am also missing the middle three fingers on my left hand from the first joint. When I explained and showed her my hand, she recoiled in horror. To be honest, it was very 'over the top', and it took her a good few minutes to 'recover her composure'. I carry a photograph on my phone of me on the day I was born... I was born with many conditions including a bilateral cleft lip and palate, the hand issue, missing my left big toe, hydrocephalus, a heart murmur, to name but a few! I plucked up the courage to show her. Her reaction was hellish. Her comment was, 'WHAT IS THAT? Oh my God, why would you have a photo of THAT?'

I replied quite casually, 'Because it's me!'

She then realised why my face was as it was and said, 'Is it because of a cleft thing?' I gave a VERY brief explanation of why I looked as I did in it and then changed the subject. The other two people in the class were totally the opposite – they were really lovely about it. I was amazed really that a photographer would show such 'horror' to me, as yes, I do look different, but I am proud of the person I am, and how I've dealt with the health problems I have. Had it not been for my family and friends support, I may not have been so lucky.” **Linzie**

Managing It

Assumptions

- Techniques used = **EXPLAIN** – **REASSURE** – **DISTRACT**

When people make false assumptions about your child, one way to deal with this is to let the person know there is more to your child than how they look. This could be done by starting a conversation, talking about things your child is interested in or telling people about your child.

It may help to be aware of the assumptions you make. Think about how you feel in a new situation. Have you already decided how people will act or what they will say? By recognising the expectations you have, this may help you to put these aside and learn to approach people more openly.

“Faith in the goodness of people”: "I immediately assume people I meet, from day-to-day, make instant judgements, based solely on how I look. It is more often the case that the only person making any assumptions is me. Recently I did a charity bag pack at a local supermarket which involved meeting a lot of new people and without exception they were all perfectly pleasant while some were even up for a chat. That was proof enough to me if I put my faith in the goodness of people it will by and large be returned. To give yourself a chance at happiness, I think you need to give others a chance as well and don't let the ignorant few distort your expectations of everyone else." **Mark**

Be prepared

- Techniques used = **EXPLAIN** – **REASSURE** – **DISTRACT**

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?

What you would like to gain from this experience and what can you 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 somewhere new with someone you know will support and help you out like a friend, or a family member. You could chat to the group leader if it is an organised activity and explain your concerns and ask for some introductions. Perhaps you can prepare some small-talk to rely on in these situations (for 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.

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.

“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:

“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.

“What is your son’s name?”

“Do you live nearby?”

“I got very little sleep last night. Marla is teething.”

“I wondered if you knew of a good child minder - I am going back to work soon?”

Finding out about your child's condition

The challenge

Coming to terms with medical jargon and understanding what treatment is available can be daunting. Sometimes it can be hard to get the information that you ask for from your child's doctor or other health care professionals, especially if you don't feel very confident or assertive. Parents can sometimes feel like they are not in charge of their child's situation or left in the dark and controlled by others.

Managing it

- Techniques used = **EXPLAIN**

You may find it useful to gather as much information about your child's condition and the treatment options available. This can give you a sense of being in control of the situation. Research shows that if someone is involved their treatment, they are able to make more informed choices – this means they manage their condition better and can explain things to people more easily when asked about it.

Information can be gathered in many ways, by talking to medical professionals, getting in touch with support groups or other organisations and researching literature and websites (although make sure the websites you look at have a good reputation). [Changing Faces Practitioners](#) can't give medical advice or recommend treatment, but can help with talking it through, give you information and signpost you to places to find out more.

It's natural to want to find treatments that will bring physical relief to your child, improve the way they function or help your child to look how they want to. However, it is important to:

- Know all the facts
- Explore the risks
- Acknowledge the limitations

It can be difficult if you have placed all your hope in treatment. Try to stay balanced and remember there may not be an answer - in most cases, it is rare for a disfigurement to be completely removed. This may make it easier to avoid disappointment or unhappiness with the results. Also, medical procedures are not necessarily the solution if you and your child are struggling emotionally with her condition or finding it hard to adapt to it. You may need other [support](#) to help with this.

Family and friends may also feel that there must be a 'fix' – and may encourage you to seek treatments. These may be your closest friends and family who care very much and who are also trying to process the situation. Sometimes people can get a bit stuck and focused on making suggestions and offering reassurance. Although well intentioned, if you are feeling ground down by lots of questions and reassurance you might want to consider letting those around you know that you are finding it hard to talk over and over again about your situation.

Being well informed can help you to talk to them about their expectations too and it may be worth suggesting they get further support. Either way, it is you and your child's choice whether to have any treatment or not.

“I’ve always found that surgery disrupts my life too much”: “I haven’t had surgery for 16 years, and then it was only as a necessity, though other people seem to think that plastic surgery will give me a perfect face. I had countless operations between the ages of 5 and 14 and found it really hurtful in my 20’s when a very ignorant work colleague asked if I’d ever considered plastic surgery! I’ve always found that surgery disrupts my life too much – missing school, having time off work, etc. My plastic surgeon thought it was great that I was happy with who I am, realised the limitations of surgery and said to me ‘if it isn’t broken don’t fix it.’” **Alison**

When considering treatment options, you might find it helpful to think about the following questions:

- What makes this the right option for my child at this time?
- Am I doing this for my child, or trying to please others?
- What difference will the treatment make to my child’s life? What will it enable him to do that he doesn’t currently do? How will this show? Am I being realistic?
- Do I know and understand all of the risks as well as the benefits?
- Do I know what to expect from the treatment? How long will the recovery process take? What will my child look like after?
- What alternatives, if any, exist?
- Can the operation wait until my child is older?
- Would it be helpful to speak with other people who have undergone similar treatment?

Looking after yourself

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

There are 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 reading lots of information might feel too much. You can always return to the parent guides at a time that feels right. Focus on what is important, or what needs your attention right now. Give yourself some space and time and make sure you take care of yourself and get the help you need.

As a parent you might be unsure of what support you want or need, or what is available. This can be confusing and leave you feeling overwhelmed. It may help to give some time and recognition to what you have been through and to know that you are not alone. Your experience will be personal to you; however there will be many parents in similar situations.

Many parents find it helpful and reassuring to talk to someone who understands the unique situation they are in. It can be beneficial to be able to express your feelings openly, either on your own or with a partner, about having a child who looks different. Interacting with others, especially other parents may also be of benefit to you. [Changing Faces Practitioners](#) can provide professional support, information and advice.

Feelings of loss

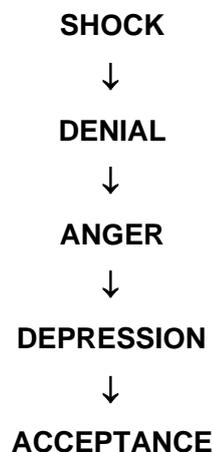
The Challenge

Loss comes in many forms – the death of someone close to you or the loss of something you value. There can also be a sense of loss if your child was born with a disfigurement, or acquired it in early life. This is likely to be a loss of how you imagine life might have been for your child if they didn't look so different. Some people imagine that life would have been much easier or their child would have been more successful.

Managing it

- Techniques used = **EXPLAIN** – **REASSURE**

You may need to go through the stages of the grieving process, including:



Although these are often referred to as 'stages', the reality is that people can experience one of more of these feelings at different times, and may go back and forth between them.

Some people find it useful to think of their child's different appearance as a loss – and feel that they need to face the stages of grief and move through them. It is important to look after yourself. If you feel shocked or angry or depressed... it is ok – these feelings are understandable. Give yourself time and, if you feel like it, you may find it helps to talk to someone you trust.

You might find it hard to believe that you will ever feel okay about your child's appearance but as grief progresses, most people slowly adjust and learn to deal with what has happened. This can take a long time and each person will be different.

Low self-esteem

The challenge

Earlier disfigurement: If your child was born with an unusual appearance or acquired a disfigurement early in life, she may have low self-esteem, especially if she has been teased or bullied. Your child may find it hard to feel confident or positive about herself.

Self-esteem is shaped through our interaction with other others. If children constantly experience difficulties, due to other people's reactions, it can make it harder for them to enjoy being with other children. If they have one positive experience, then they are more likely to expect a positive experience the next time and feel more confident about themselves.

Managing it

- Techniques used = **EXPLAIN** – **REASSURE**

Building self-esteem

Self-esteem is about feeling good about oneself, knowing that you are loveable and being proud of your strengths, abilities and achievements.

Parents and adults who care for a child play an important part in nurturing positive self-esteem in their child by praising them, acknowledging their unique and loveable qualities and supporting their development of social skills and emotional awareness. When children have positive social experiences, they will take on these feelings of self-worth and grow up with a sense of "I'm OK"; they will take pride in themselves and what they do.

1. Try to recognise the thoughts that make your child feel bad about herself and challenge them with something good.
2. What does your child like about himself? List your child's good points – is she caring, clever, funny, artistic, patient, sporty, a good friend?
3. List your child's achievements – these may certificates, exams, things he has done at home, it may be related to a hobby or social event like scouts... anything you are proud of him for.
4. Encourage your child to spend time with positive people, i.e.: those who make her feel good.
5. Doing positive things, i.e.: the things that your child enjoys and finds satisfying.
6. If your child has an experience that you think did not go so well, write down all the positive points, including how your child acted.

Praise your child

Children flourish when they are praised and when they know that they are loveable and likeable. Be specific in your praise - tell your child exactly what she did that you liked; comment on her

strengths, highlight her achievements and positive personality traits. This will help your child to understand what it is that you like about them. Here are some examples:

“When you told Sally about your birthmark you spoke so clearly. That made it easier for her to understand. I am proud of you for doing that.”

“I saw you smile and ask that boy to play with you. That was friendly. I see he decided to join you. It looks like you had fun.”

“I see how hard you were concentrating on your writing exercise. Well done for putting so much effort in. It looks neat.”

“You are such a good problem solver. When Jo burst into your group of friends and tried to take them away you told her you were upset and that you still wanted to play with them. Inviting her to join in really worked out well.”

“I saw you tell your friends how happy you are. That was very thoughtful. Even if they can’t see you smile they will know how you’re feeling. After a while they will learn to tell for themselves.”

Dealing with low self-esteem can be hard – [talking to a Changing Faces Practitioner](#) may help your child get there more easily.

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. Sometimes siblings feel they have to be on their best behaviour or may misbehave to get attention.

They may feel left out when their sibling goes to hospital or they may get teased or asked questions about their sibling'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 or sister's unusual appearance or looking different and to set aside time for them to share their feelings and concerns - see [Talking with Your Child](#).

Staying positive

The challenge

Often we are not aware of how we think – or how this affects the way we act. We all have expectations and make assumptions about the world around us. What we have experienced in the past can affect how we see things in the present.

Worrying about your child's condition and how other people respond may mean that, over time, you become pessimistic and expect things to go badly. This may mean you act in a negative way. For example, when you are in the school playground, you may think, *“No-one wants to talk to me because my child looks different.”* This may mean you don't end up talking to anyone – not because your child looks different, but because you do not look like you want to talk and people don't know how to approach you.

“Remaining positive... is the best path to take”: “I have found remaining positive challenging at times but can honestly say it is the best path to take. My disfigurement has made me feel inferior, unloved, inadequate at times and it is difficult to replace these feelings with positive

ones particularly if you've had negative experiences. Over the years I have also learnt that my disfigurement is a small physical part of me so I make sure that when I go out I take care with the rest of my appearance. I make sure my hair looks nice, that my clothes are presentable and I wear accessories. I find a pretty scarf or a chunky necklace distracts attention from my face."

Alison

Managing it:

- Techniques used = **REASSURE**

We can't stop thoughts coming to mind, but we can learn to recognise negative thinking – and try to challenge it. Learning to be more aware of your unhelpful thoughts will help you to see them for what they are – negative. Once you can do this, the thoughts may become less powerful and have less influence over you. To help you feel even stronger and more confident, try coming up with a positive thought instead, for example, *"People might be curious rather than unkind."* It will take practice, but when you think a negative thought, make an effort to replace it with a positive thought.

One of the ways to manage negative thoughts is through positive self-talk, 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 positive 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."

Having a more positive attitude can make a huge difference – although this may take some time. Changing Faces offers [support, advice and information](#) and you may find it helpful to talk to one of our Practitioners in more depth.

Take it at your own pace

There is a lot to think about in the sections above. It can be overwhelming to think about doing everything at once and it takes time to build up your confidence. By identifying your concerns in a clear way, you may be able to approach them step-by-step, starting with what seems manageable and then building on that.

It is often helpful to search for other organisations and condition specific support groups to obtain further advice, support and to give you and your child the opportunity to meet with other children and parents in similar situations. See our website for details of other organisations that provide information and advice.

Summary

- Your child's disfigurement, and how they feel about it, is personal to them
- Your child is not alone – one in 45 of us in the UK has a disfigurement
- Explain – reassure – distract – assert – humour
- Although some may stare, most people are curious rather than unkind
- Being prepared and thinking of things to say in advance can help
- 3-2-1 Go!
- Give yourself time and space to work through feelings of loss
- It is understandable to feel apprehensive when meeting new people.
- Try to wait and see how people respond to you and your child, rather than expecting them to be negative
- Gather information about your child's condition and any treatments
- Don't pressure yourself – approach your concerns step-by-step
- Many children learn to cope and go on to lead very fulfilled lives
- [Changing Faces](#) offers support, advice and information

Supporting and advising

Changing Faces offers information, advice and support to children, parents and adults with scars, marks or conditions that affect their appearance.

Informing

We work to improve policy and practice in organisations. Through staff training and consultancy we help to create fair and inclusive environments.

Campaigning

We campaign for social change. We aim to promote a society in which people are treated fairly and equally.

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This guide is also available, on request, in plain text and on CD

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Please contact Changing Faces for further details of sources used.

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