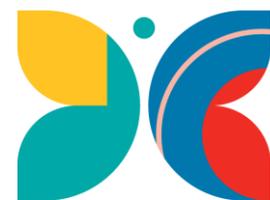


You and your baby

Parent guides



**CHANGING
FACES**

This guide aims to:

- **Support and guide you through these early days**
- **Provide some suggestions that may help**

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Discovering your newborn baby has a condition that affects the way he or she looks can be a shock. It may leave you feeling overwhelmed and concerned about what the future holds.

Many parents remember this time as the most difficult stage for them in their child's life. It can be challenging to absorb so much new, often complex medical information, on top of dealing with the many mixed emotions, as well as responses from other people.

Your feelings

Having a baby who looks different can trigger some powerful emotions that can take many parents completely by surprise. Some emotions may include: grief, loss, joy, guilt, sadness, love, confusion, shame, anger, fear and protectiveness. These are all common, and you may find yourself shifting between feeling happiness one minute and devastation the next.

Some parents describe a sense of loss at not having the baby they had prepared for. The process of coming to terms with your baby's appearance and unexpected medical needs will vary from parent to parent. Allow yourself time to talk about how you are feeling. This could be with your partner, a friend, your GP or with someone else who understands your situation, such as a Changing Faces Practitioner.

Finding out more

Gathering accurate information about your child's condition, treatment and management can help you feel more in control and less anxious. It also means when people ask you questions you'll have the right words and information to use. Information can come from the medical professionals supporting you and your child and from your own research.

Make a list of questions you want to ask in preparation for meeting with medical staff, for example:

- *"Why does my baby look different?"*
- *"What is the name of the condition?"*
- *"What are its effects?"*
- *"How might it affect my child later?"*
- *"What about treatments?"*
- *"What makes this the right option for my baby at this time?"*
- *"Am I having treatment for my baby, or trying to please others?"*
- *"What difference will treatment make to my child's life? What activities will it affect? 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 baby look like after?”*
- *“What alternatives, if any, exist?”*
- *Can an operation wait until my baby is older?”*
- *“Would it be helpful to speak with other parents whose babies have undergone similar treatment?”*

When your baby is in hospital

Many babies with conditions also need medical treatment. This can be very distressing to see and you may naturally feel quite powerless and scared. It can help to remind yourself that agreeing to medical treatment is a way of caring for your baby. It can feel difficult, especially if you cannot hold your baby through some of the treatments, however, touching, talking and being close by can all still be very comforting for both of you.

Telling people about your new baby

Announcing your baby’s birth can cause anxiety, especially if you are unsure what to say about your baby’s condition and appearance, or perhaps you are unsure whether to say anything at all.

Friends and family can vary in the ways they respond to your baby’s appearance and with the level of support they offer. Some will be caring, accepting and will give invaluable support to you and your baby. You may find that others are more uncomfortable or don’t behave in the way that you expect. Others may need a bit more time to adapt to the situation. This can be hard to deal with. Many parents find it helpful to spend time with those who are able to offer more support.

When you introduce your baby to friends and family you might want to share a little information about their condition as well as other information. This can be done by phone, text, letter, e-mail or in person. Here’s an example of something you could say:

“I am looking forward to seeing you. I wanted to let you know that the left side of Joshua’s face is smaller than his right and his eye is droopy on that side. It is a bit of a shock when you first see him. We are getting used to it now and he’s got big blue eyes and lots of brown hair.”

There will be times when you might not feel like talking about your baby; it is okay to let your friends and family know this. For example:

“I am looking forward to seeing you all but don’t want to talk about it a lot”.

For many parents the use of Facebook and other social media may be a quick way of announcing the birth; however, this way of communicating can have the additional pressure and expectation to share photos of your baby. Don’t feel you have to succumb to the pressure; do what feels right for you. You may decide to post a picture of your baby or perhaps do it later when you feel more prepared.

Going out in public and meeting new people

Many parents report feeling completely unprepared to deal with the reactions from strangers they meet, which can leave them feeling anxious about going out. More often than not, such curiosity or concern is a natural human response to seeing something different for the first time.

Changing Faces has identified five simple techniques to manage a range of situations:

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 and when to use it. There is a lot more information about the techniques and managing the challenges in [You and your child](#) and [Communicating with confidence](#).

Responding to people’s curiosity

Try the **EXPLAIN – REASSURE – DISTRACT** technique.

EXPLAIN – REASSURE – It can be helpful to have a brief explanation ready when you notice someone staring at your baby or if they ask a question. This can diffuse an awkward situation and help people to move beyond their initial reactions.

For example *“Maria’s face is swollen on one side. It doesn’t hurt her”.*

DISTRACT - you don't have to continue talking about your baby's difference. You can move the conversation on to something else or end it politely.

For example, *"We don't mind talking about Josh's Aperts but we do need to get going now"*.

The future

If you find yourself overwhelmed by concerns about the future it can help to focus on the present and what you need to support you and your baby right now. Feelings of sadness or helplessness do lessen but this can take time.

Getting support

Just as every family's experience is different, so too are the ways that families start to move forward. Remember to:

- Take care of yourself and go at your own pace
- Say as little or as much as you want to other people
- Let others help you

For information and advice on managing the reactions of other people when you are out with your baby, and talking with your child about their appearance, see [You and your child](#), [Communicating with confidence](#) and [Talking with your child](#).

At Changing Faces we speak with many parents during this time and can support you if you are finding it hard talk about your baby's condition. It might help to talk to a practitioner on 020 7391 9282 or email support@changingfaces.org.uk

Summary

- Give yourself time and space to work through your feelings
- Gather information about your child's condition and any treatments
- Although some may stare, most people are curious rather than unkind
- Say as little or as much as you want to people you meet
- Have a brief explanation ready **EXPLAIN – REASSURE – DISTRACT**
- Don't pressure yourself – approach situations at your own pace
- [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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