

0-3 years. Guides for Parents

Guide 1. When your baby looks different

Like any parent, you are probably feeling overjoyed (and exhausted) following the birth of your baby. Discovering that she has a visible difference may also leave you feeling overwhelmed and concerned about what the future now holds. Many parents remember this time as the most difficult stage in their child's life because they not only have to absorb so much new and complex information but they also have to deal with many conflicting emotions.

She may have needed medical treatment at birth, soon after or be facing treatment throughout childhood. You may have a clear picture of how your child's condition or difference will affect her or this may still be uncertain. You may be feeling left out whilst other people take care of your baby. You might have lots of support or you might feel hurt by the reactions of medical staff, friends and family.

Just as every family's experience is different, so too are the ways that families start to move forward. This guide can help you to understand and manage what you may be experiencing at this time. It also provides some practical suggestions to help you and your baby to adjust to this unexpected journey.

1 FINDING OUT ABOUT YOUR BABY'S CONDITION

Learning that your newborn son or daughter has a disfigurement is a shock for every parent whether you have known about it for a long time or not.

Some parents are informed about their baby's condition in a clear and considerate manner which is backed up by offers of support. Other parents may feel rushed, upset or confused by the content or the unsympathetic way the information is given. Feelings of grief and loss at this time are understandable and it helps to look for support for you and family at this time. This is especially important if your baby has a rare or complex condition which remains undiagnosed for some time.

Gathering accurate information about your child's condition and its treatment or management can help you to feel less anxious and helpless and many parents often spend a lot of time doing this either before their child's birth if they've received a pre-natal diagnosis or afterwards.

The main sources of information are from professionals (e.g. a consultant or specialist nurse), support groups or the Internet. You may want to look at pictures of babies born with a similar condition or find out how you can care for any special needs she may have (e.g. feeding or surgery soon after birth).

If you are looking for information on the Internet or from support groups, it is important to remember that medical conditions affect children in different ways so it is 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 her 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

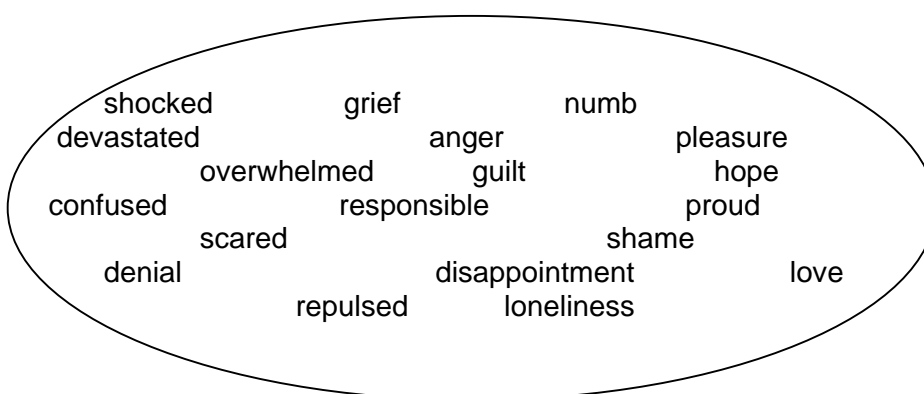
Judge: 'Websites for Health' Project

www.judgehealth.org.uk

2 YOUR FEELINGS

Having a baby who has a visible difference can trigger off some powerful and conflicting emotions and the force of them can take many parents by surprise. Some parents report swinging from joy to devastation, from grief to hope, from anger to pride in their baby. Others may feel stuck in their feelings of anger or self-blame and feel unable to move forward.

You may have experienced some of these feelings before and after the birth of your child. It can help to recognise that they are part of the process of adjusting and coming to terms with your baby's appearance and unexpected medical needs. Parents often feel guilty about these feelings so we have listed the most common feelings that parents describe to reassure you that they are all natural, understandable and shared by many others.



Some parents speak with us about how they find it hard to look at or hold their baby. Others say that they feel embarrassed or ashamed of their baby. If you are struggling with these very difficult feelings don't be hard on yourself. Try to think about your baby in terms of something other than her appearance or condition. For example, when you look at her you can think, "She is alive. What a miracle." or "She seems so peaceful." or "She is so lively."

Remember, you can have mixed feelings about your baby. It doesn't mean that you don't love them.

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 baby who has a visible difference.

You can contact *Changing Faces* on 0845 4500 275 or email info@changingfaces.org.uk for professional support, information and advice. Alternatively, you could speak to your GP's or to a specialist or nurse at the hospital. Do try talking to your partner, your family or your friends if you feel that they can listen and accept your feelings at this time.

3 BONDING WITH YOUR BABY IN HOSPITAL

Many babies who have disfigurements need medical treatment either at birth or throughout childhood. It is very distressing to see your baby having medical treatment and you may naturally feel quite powerless and scared. It's essential to keep reminding yourself that you are protecting, nurturing and loving your baby by enabling her to have the care she needs from skilled professionals even if it means she is separated from you for a little while.

Parents are always encouraged to hold, cuddle and feed their baby but this may not be possible if your baby needs intensive medical care or surgery. Whatever the length of your baby's hospitalisation, here are some ideas on how you can continue to care and comfort your baby.

A. Touch

Often parents feel quite upset and disappointed if they are unable to cradle and cuddle their baby, worrying that they and their baby are missing out on bonding. Yet babies respond positively to warmth and comfort offered through any human contact, such as holding your baby's hand, caressing her foot, or stroking her finger.

B. Presence

Being unable to touch your baby as she undergoes medical treatment can be very traumatic and it's important to reassure yourself by knowing that a baby feels secure and safe just with you standing near to them. Babies can sense someone familiar and feel cared for in this way.

C. Voice

Talking softly and lovingly to your baby, even if you are unsure whether she can hear you, is a positive way to nurture your baby. Tell her you want to hold her close, let her know that you are there and that you love her.

D. Eye Contact

Eye contact can reassure your baby that you are with them and it is a useful way of reaffirming your bond. Babies naturally look about them and eye contact helps them to feel connected to you and loved.

You can continue to use these ideas to bond with your baby when you take her home.

4 CARING FOR YOUR BABY AT HOME

Many new parents feel uncertain about how to look after a baby when they bring them home. Not only do you have a tiny baby, but you are in an stressful situation which has unique challenges. If your partner, a friend or a relative is happy to help care for your baby or sit with her, then let them as it will give you time to adjust or just have a break.

If you are worried about how best to care for your baby at home, try talking to the staff at the hospital as they are used to these situations (particularly in regional centres) and can offer support and advice. You can also take a look at a *Changing Faces*' Guide called *Finding Further Support*.

5 CARING FOR YOURSELF

Often parents are so thrown by the whirlwind of emotions and experiences that they forget to take care of themselves. Remind yourself that the more you take care of yourself, the more you will be able to take care of your baby. Take the time to have a soak in a hot bath, go for a coffee with a friend or ask for a cuddle from a loved one. Ask others to help out by having your other children to stay for a night or making up some food for your family.

Many parents talk to us about how hard they find it to talk with other family members or friends about feelings that they think are shameful or wrong or make them sound like a bad parent. But the way you are feeling, although this may be intense, changeable and overwhelming, is natural and shared by other parents in similar situations. It is helpful for a Mum or Dad to talk over these feelings as a way to start moving forward and adjusting. Sometimes it might be easier to speak with a specialist at *Changing Faces* about this.

6 RESPONDING TO YOUR BABY IF COMMUNICATION IS LIMITED

You may be unsure how to react if your baby's condition affects her ability to express herself; she may be unable to smile, cry, see or hear. If you are in this situation, it does not mean that you cannot bond or communicate with your baby. It just means that this will not happen in the way you might expect and you may need to learn new ways to understand her.

Try talking to her, even if you are unsure whether she can hear, see or understand you. Make sure she is calm, that you have her attention and make eye contact if you can. Even if your child does not understand the words you are using, she will pick up on your tone and facial expressions. If you are comfortable, calm and confident in doing this, she will feel comfortable too.

- Use touch and eye contact to ensure that a baby with a hearing impairment is looking at you and can see you smiling, talking or signing.
- Use 'feeling words' to describe how you think your baby is feeling by looking for clues from her behaviour. A baby who cannot smile will show happiness in other ways (e.g. not crying, being interested in what is going on around her, giggling or gurgling), whilst a baby who cannot cry will still show distress in her body. For example, "You're eyes are twinkling, I can see that you're happy."
- Try reading her body language. Is she turning away from you or trying to get closer to you? Is she looking at you or at something else? For example, "I see that you legs are kicking excitedly. Are you happy to see Daddy?"
- Listen to her voice. Does she sound happy or sad? Is she screaming in anger or is she hungry?

To find out more about communicating with your baby speak to hospital staff or contact *Changing Faces* for information on other organisations that can help.

7 INTRODUCING YOUR BABY TO FAMILY AND FRIENDS

Announcing your baby's birth

Announcing your baby's birth can cause anxiety if you are unsure what to say about your baby's condition or if to say anything at all. If you can share a little information about your baby to help people over their initial surprise or shock it can ease your own worries about other people's reactions.

Some parents send out a birth announcement card which includes a photo of the whole family, their baby's name, weight and date of birth, and a little information about the condition. It's best to keep this information simple – the name of the condition, what it looks like and how it affects your baby. Also include one way that she is similar to you.

EXAMPLE

We're delighted to announce the birth of our daughter Hannah Louise on 8th May 2006. She weighed in at 6lbs 8oz. She has a red birthmark on her cheek which we call her strawberry. She's got masses of jet black hair just like Mummy. We'll be home soon and would love to see you.

Love from Martin, Rosie and baby Hannah.

Some parents prefer to tell people over the phone or in person. Again, it helps to mention things other than just her appearance or condition so that people can get to know her.

EXAMPLE

"I am looking forward to seeing you. I wanted to let you know that the left side of Sabine's face is smaller than her right and her eye is droopy on that side. It is a bit of a shock when you first see her. We are getting used to it now and she's got the biggest smile you've ever seen."

Getting support from friends and family

The response and levels of support from friends and family to your baby's appearance can vary. Some family members and friends are caring, helpful and accepting and will give invaluable support to you and your baby.

Sometimes you might not feel like talking about your baby's condition and it's OK to let your friends and family know this. By being gentle and firm about what you want, you can get the support you need.

EXAMPLE

"I am looking forward to seeing you but don't want to talk about it a lot. What I really want is a hug and to enjoy your company."

But it can be hard when some family and friends act as if nothing has happened or don't call and visit as often as you expected. If you sense that someone is avoiding you or

doesn't know what to say, it can help to make the first move as you will feel more in control of the situation. Try calling or sending an email saying something like, "I hope you're well. We've all been really busy with Amy and it would be great to catch up soon so I can tell you about her and find out what's happening with you."

If this doesn't open up the lines of communication, it can be painful. Try giving the person a bit more time and put your energies into family and friends who are supportive.

Taking your baby out

For information and advice on managing the reactions of strangers when you are out and about with your baby take a look at the *Changing Faces* Guide called *Meeting People and Feeling Good*.

8 INTRODUCING YOUR BABY TO HER VISIBLE DIFFERENCE

It may seem unnecessary to speak with your baby about her disfigurement but she is learning and soaking up all that goes on around her even though she cannot communicate through language. She can also discern emotions from early on and will respond to how you say things. Being able to talk confidently and openly about your baby's visible difference will show her that you are happy to talk about the way she looks and are comfortable with it.

Start talking about her difference from early on by introducing the topic through daily activities. Bedtime stories, playing, face-to-face contact, photos, bath time, looking in a mirror, applying cream or administering medicine are some of the opportunities you can use to talk to your baby.

EXAMPLE

When looking at your infant you may comment on her hair colour, or name her features or you may hold her up to the mirror so that she can see herself. "This is your nose, your mouth, your ears." If you are pointing out your child's nose, eyes and mouth, don't forget to mention their birthmark, their special fingers or their small ear. It is natural to talk about appearance and a baby will, over time, pick up if something is left out of the conversation.

The key to explaining things is to keep it simple, be open and honest and use language that your child will grow to understand.

- Finding a whole sentence or two to say about your child's appearance can feel uncomfortable. Try just giving it a name to start with.
- Use words that describe what a visible difference looks like e.g., think about the colour, shape, size and texture of your child's difference.
- Use the medical name (if there is one) in conjunction with simple explanations about what the mark, scar, asymmetry etc looks like and how it affects your child.
- Positive names for a child's condition like "your special mark" or "special ear" are fantastic in helping a child feel confident about their appearance but use the medical name too so that she learns it is OK to talk about her condition.

EXAMPLES

- "This is your small ear, this is your big ear."
- "You were born with Moebius. Your face doesn't show your smile but I can hear it in

your excited giggles.”

- “This is your birthmark.”
- “This is your cleft. The doctors will fix it soon.”
- “This is your Strawberry mark.”
- “You were born with a hole in your lip. This is the scar left after the doctors fixed it.”
- “These are blisters you get on your skin. They make your skin red and sore to touch.”
- “You were born with Nf. That is why you have these little bumps on your skin.”

You can then move the conversation on to something else (e.g. the sounds you and your baby can hear, the things you can see around you).

If you are finding it hard to talk about your baby’s condition, it might help to talk to a specialist at *Changing Faces*. Also, take a look at the *Changing Faces’ Guide on Finding Further Support*.

9 SIBLINGS

When a baby is born with a disfigurement, there are unexpected adjustments for siblings too. They may be left with relatives or friends while you spend time at the hospital with your baby. Siblings may not only be jealous of the attention the new baby is getting but also worried about the way she looks and her health.

It is useful to know that most siblings cope well with a having a brother or sister with a visible difference. They will be curious and concerned so it is helpful if they can be supported to understand and accept their brother or sister’s appearance. You can do this by giving them information about the condition, why she is in hospital or having medical treatment and how they can explain her unusual appearance to others.

There are more ideas on explaining a visible difference is in the *Changing Faces Guide on Talking to Children about Difference*

10 THINKING ABOUT YOUR CHILD’S FUTURE

Although you may feel bowled over by everything that has happened, babies, parents and families are able to adjust, just as we all do with other events in our lives. Sometimes it’s useful to think of other difficult situations that you coped with or acknowledge that your negative feelings about the event are not the same as your feelings about your baby. Many parents tell us how they find ways to bond and love; find ways of coping with their baby’s medical needs, her appearance and the challenges these may bring.

You may already be thinking about whether your child will fit in at school, whether she will be teased, whether her condition will affect her physical and mental abilities or whether she will be loved by others for who she is. These anxieties may be influenced by your personal experiences (you may have been teased at school or struggled to fit in) or they may be influenced by your beliefs (only certain people fit in and get good jobs) or present feelings (feeling overwhelmed).

Whatever their origin, these are normal anxieties shared by many parents. If you find yourself overwhelmed by concerns for the future it can help to focus on the present and what you need to support you and your baby right now.

Give yourself time, try not to judge yourself, praise your achievements and abilities, let others help you with practical support, emotional support and take advice from people who have experience in this area. Feelings of sadness or helplessness do subside and give way to new hopes for your child.

As time goes on you can move away from focusing constantly on your concerns or the difficulties and start to focus on what is happening for your child now. You can start to acknowledge and enjoy your child's latest achievement (like eating her first solids, sitting up, walking or going to playgroup) and look forward to the future with new hopes and realistic expectations.