

If your baby is different

This is a general guide. Everyone is different.

You may find you are very sensitive to people you meet when you are out and about with your baby. You may not be sure whether other people realise your baby is different and has a condition. You can choose whether or not to mention it.

Many new parents go through a grief process as they would if their baby had died. The dream baby you imagined for nine months or more, the baby without this condition, is not there. But you still have a baby needing your love and care. So in addition to the grief for the loss of your dream baby, you develop feelings of love and joy for the actual baby.

Grief is a healthy reaction to loss. The strength of your reaction depends on how big the loss seems to you. Grief is hard work and it hurts. It can be delayed (maybe your baby is very sick and their actual condition seems unimportant) but it cannot be avoided.

Throughout your child's life there are likely to be times when you revisit these feelings of grief and sadness but most parents say the pain of the early days is the hardest. Our experiences show that there are many different feelings associated with the grieving process.

Denial is a common first reaction, you hear the news and think '*This isn't really happening*' or '*This only happens to other people*'. It cushions the blow and protects you for a while until your body is better able to cope with the news.

Anger may be generalised rage at the world or a more personal '*Why me?*', '*How dare this happen to me?*' You may be able to channel your anger into doing something to help your child.

Bargaining is that feeling of '*If I do this I can make it better*', a time where guilt and responsibility may be strongly felt. It may lead to a change in priorities in your life.

Depression is an intense and overwhelming feeling of helplessness and sadness, '*My world is falling apart*'.

Acceptance creeps in as you start to think, '*So my baby has Down's syndrome, I can live with that*'. Most people don't work through these feelings in order. They may experience them all at once and revisit them time and time again. Your partner may well react differently to you.

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Looking after yourselves

Your own health is vitally important. Any birth brings with it a complicated mixture of physical and emotional reactions. In addition to experiencing all of these, you are also coming to terms with your new baby with a special condition.

Expect good days and bad days and let yourself cry if you need to.

Rest. You need rest like all new parents who have just had a baby.

Spoil yourself. Enjoy your favourite treats.

Get information. Fear of the unknown may make things harder, ask questions, BUT only read information that helps you, don't get overwhelmed.

Allow yourself time to heal. Your feelings will change, things will get easier.

Get to know your baby. Cuddle your baby, breastfeed, take photos. Take time out. Visit somewhere peaceful or just forget about the condition your baby has for a while.

Talk to another parent. Try to find out about your local parent support group for your baby's condition Picking up the phone that first time can be very hard, but it really helps to talk to someone else who's been through it.

Ignore unhelpful comments. Even if they're from people close to you!

Write a diary. Or express your feelings in art or music.

Telling others

Brothers and sisters

As a parent, you are best placed to decide how much information is appropriate to give your children. Much depends on their age, their level of understanding and their curiosity. Don't be afraid to involve your children as soon as possible. It's OK to show them you hurt – they may well realise that already. Tell them in an honest and open way. They may not understand or remember all the information, so follow their lead, keep listening and answer their questions. Follow your children's lead in deciding what else to tell them.

You may want to cover things like:

- It's not your fault the baby has this syndrome, it just happened by chance.
- Babies with certain syndromes find it hard to learn new things. They will want to join in and do the things you like doing but they might take longer learning how to do it and they may not be good at it.
- The baby will always have this condition/syndrome.

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- You can't catch it.
- Brothers and sisters are very important to a baby.
- We love you very much and we love the baby too.

Your children will follow your lead. If you treat the condition as just one aspect of your baby's life, your children will too.

Other people

Telling family and friends can be very hard. Only you know when and how it is best to tell other people. Sometimes you need to tell close friends or family so you have someone to cry with.

Sometimes it is easier to tell one of your friends and ask them to pass the information around so that people know before they talk to you.

Sometimes it is best to wait until you have come to terms with the news yourself and are able to cope with the other person's reaction. Only you can decide how much of your baby's story to tell someone and which words to use.

Sometimes family, friends and people you meet say very insensitive and hurtful things. Try to ignore these comments. They are often based on misunderstandings. People will follow your lead. If you are open, honest and positive about the condition, they will be too.

Adapted from Down's syndrome – a new parents guide, Stuart Mills, Down's Syndrome Association, 2007, www.downs-syndrome.org.uk

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ABOUT US
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Welcome

TO HOLLAND

by Emily Perl Kingsley
Print Version

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome To Holland".

"Holland?!" you say, "What do you mean "Holland"??? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy"

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes that's where I was supposed to go. That's what I had planned".

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

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PARENT RESOURCES

- GENERAL INFO & NEW PARENT PACKAGE
- IN-DEPTH RESOURCES
- PRESENTATION CENTER
- HELPFUL LINKS