Information about babies with Down's syndrome for new parents.

Down's Syndrome Scotland

helping people realise their potential

Getting to know a baby with Down's syndrome

For more information or to obtain any of our other publications please visit www.dsscotland.org.uk

Daniel

Hearing the news

Some parents know from screening tests that their baby will have Down's syndrome while others have no idea until after the birth.

However, even when doctors inform you in a sensitive and positive manner the news may come as a shock.

Callum

A mum's perspective

Claire

When Emma was born I was 19 years old. All the way through my pregnancy until the birth I never knew that Emma had Down's syndrome so when she was born it was a total shock to everyone. My initial thoughts were questioning myself as to how it had happened, how I was going to cope and wondering about the kind of life she would have.

I didn't tell anyone how I was feeling, not even my family, it was something I decided to deal with on my own. Emma was taken straight into intensive care so I didn't see her for 24 hours as I had to recover myself. I decided to go to see her on my own and see how I felt. The minute I saw her and held her I fell in love and it was there and then I knew that I was ready to face anything that came up.

It wasn't easy dealing with appointments galore, specialists and everything else that was a necessity, but she gave so much back to me I don't think it mattered. Nearly 7 years on, I've never looked back or questioned my decision to stand by her. She's such a loving child to everyone she meets and she makes me so proud every day.

Karina

When Holly was born Jamie and I were so happy and excited to meet her. When we first saw her little face we were so emotional. She was perfect and absolutely beautiful. The consultant spoke poor English and told us that Holly didn't look like us which confused us. When we realised that he was trying to say that Holly had Down's syndrome we were annoyed at him for not saying that in the first place although our feelings towards Holly never changed.

When it was confirmed that she had Down's syndrome it was emotional because we were worried for her. Later on we did have up and down days. The down days were mainly because we were concerned about her future and also how to best explain to her big brother. Lack of knowledge was the main thing that caused us to be so emotional when Holly was born.

Now, ten months on, Jamie and I have more knowledge about Down's syndrome and can see that Holly is no different to any other baby her age. Our worries and concerns have lessened. Meeting people and having support from Down's Syndrome Scotland have helped us to be the parents we hoped to be for Holly. Our feelings towards Holly have never changed and we still see her as our perfect beautiful daughter.

Holly

Brenda

I felt like we were being punished and what had we done to deserve this. I also worried about what the whole of Jane's life might be like and I started worrying about schools, education, where she would maybe work, live and what would happen when my husband and I were no longer around. I had her whole life mapped out within 3-4 days of her being born.

I certainly hadn't considered any of these things when her older brother was born. I wanted answers about how and why this had occurred. I read lots of information about Down's syndrome and eventually calmed down, settled down and got on with things. I also remember saying to my Mum, "I feel like I've been given a life sentence!" At that time I would have changed things if I could in an instant.

However, now I couldn't contemplate things any other way. My daughter has been such a great educator to our family and the community as a whole. We are a much stronger family unit than we might otherwise have been because she is part of it.

Her relationship with her siblings is fantastic and they are much more patient, understanding and tolerant than they may have been otherwise.

Jane

Cindy

When Michael was born he was placed on my chest and as soon as I saw his eyes I said, ”Oh, he’s got Down’s syndrome!”. I had two midwives with me, one who was in training. They both fell silent and my husband said, “sshh ..no he hasn’t”. I said to him, “don’t be silly, look at his eyes.” Nobody in the room said a word or even acknowledged I had said anything.

When the doctors came to see me after they had taken him away they asked, “does he look like anyone in your family?” I had no idea what they meant but realised quickly that they were referring to him having Down’s syndrome. I told them, “only my cousin who also had Down’s syndrome.” Their response was, “we think he is too. We’re sorry” and left the room. I thought this was silly as I had been first to spot it and bring it up. We were left on our own for hours and I felt like it was because nobody knew what to say to us.

All we were worried about was finding out if his heart was okay which thankfully it is. We decided that night to enjoy every day we have with him. In relation to how I felt when he was born, I wasn’t surprised. I knew something was different all the way through my pregnancy but no-one would listen to me.

Everything made sense. I felt like we were being avoided by the staff because everyone assumed we would be feeling upset because he had Down’s syndrome, but we weren’t. I just wanted to hold him.

Michael

A dad's perspective

Neil

"We knew there was a 50/50 chance Ruby would have Down's syndrome from early on in Tracii's pregnancy. I didn't know that much about it but one of my best friends from school had a younger sister, Faith, who had Down's syndrome and I knew her and that she and her family were happy.

I had felt Ruby would have Down's syndrome for some reason and when her and her twin sister Darby were born, we knew for sure. I had wondered about how she would be different to her twin and how this would affect them both growing up.

Any doubts I had have gone, as Ruby is her own person and seeing her reach her milestones is as rewarding as Darby's, no matter if she reaches them later. Seeing her determination to do what she sees her sister already doing, and how she's developed with all the help we've had has been a joy.

I can't think of Ruby being any other way. I can see her personality coming through, as well as mine and her mum's traits. I know there's challenges ahead, but Ruby seems up for it which makes me think I am too."

Ruby with Dad Neil

Graham

When my Daughter Nina was born with Down's syndrome, it was a complete shock, because we had no advance warning. We went through the 5 stages of grief in 24 hours, as we wrestled to understand what this diagnosis meant. It's fair to say that it's very easy to let your emotions run away with you at this point.

So, for me, I wanted to understand what I was dealing with, and subsequently, I read huge amounts of background information very quickly, which gave me a handle on things and I began to understand that children with Down's syndrome are as individual and unique as everyone else; this was a huge comfort.

I also understood quickly, that although I couldn't control that my baby was born with Down's syndrome, I could control how I responded to it. Acceptance or resistance - and I chose acceptance.

Twenty months on, Nina is confounding all expectations. She walked from 18 months, she is being toilet trained and is hitting all milestones as normal, including going to a community nursery 3 mornings a week; we are also lucky that she was born without any additional health issues.

In summary, Nina is an amazing baby with the personality to light up a room. For me as Dad, she's the best thing ever to happen to me, because she's made me grow as a person."

Graham and Nina

Dean

Initially when I was told about Dillan's condition shortly after his birth, I was primarily concerned about the possible negative health aspects I had heard about. As the main worry of early heart defects was ruled out, I began to realise that my new partner in crime was handsome and healthy and that was all that mattered.

My son is now 21 months old and when I look at him I don't acknowledge that he has Down's syndrome, I just see my wee man who loves music as much as I do and spinning tops. Every other week seems to present a new hurdle (therapy appointments, fighting for his equal rights at his nursery, amongst many others) but they fade into insignificance when he says, "Hello Daddy" with a smile when I come home from work.

Enjoy your journey is the only advice that I can offer to you taking your first steps with your young one. Having a strong co-pilot helps too; thank you to my wife Maya for her time and love invested to make sure Dillan is healthy and ready for the world."

Dean and Dillan

Early days

Having a baby is an exciting but also a tiring time for new parents. When you are told that your newborn baby has Down's syndrome it is quite natural to experience differing emotions ranging from:

It is very common for parents of a new baby who has Down's syndrome to experience a number of emotions at any given time, particularly during the first few weeks and months.

It is important to realise that as parents you have not done anything to cause Down's syndrome and these feelings are totally natural and experienced by many parents.

Support and information

Support and information is available from our Family Support Team:

Down's Syndrome Scotland
Tel: 0131 442 8840
www.dsscotland.org.uk

What is Down's syndrome?

Down's syndrome occurs at conception when there is an extra copy of chromosome 21, meaning that they have three 21st chromosomes which is why it can also be known as 'Trisomy 21'. This is the most common type of Down's syndrome. It occurs worldwide and does not depend on your ethnicity or race.

The condition is named after a British doctor, John Langdon Down, who identified it in 1886. However, it was not until 1959 that the chromosome abnormality was found. The effects of this extra chromosome vary greatly in different people. It does cause changes to some physical characteristics, a degree of learning disability and some people also have additional health problems.

Everyone with Down's syndrome is unique and no one can predict how your child will develop. However as some of the stories you have already read and many more you hear, as your child grows demonstrate; people with Down's syndrome can make the most of their abilities and live happy fulfilling lives.

Everyone with Down's syndrome is unique and no one can predict how your child will develop.

Sharing your news

Family members and friends

It's not always easy to break the news to relatives and friends, especially when you are perhaps feeling vulnerable yourself. People's reactions will vary and sometimes they will look to be led by you.

If they see you treating your baby as a valued and loved individual that will greatly influence their response. Close family members e.g. Grandparents may also experience similar mixed emotions that you are going through, like those mentioned on page 9. Try to involve people in caring for your baby. Practical tasks can help both them and you. Reassure friends that your baby is not fragile and needs to be treated like any other baby.

A grandparents perspective

"Although I used to be a general surgeon, when my wife was expecting each of our three children I was always very anxious. By this I meant I did not feel I could possibly cope if one was born with a disability.

Thereafter, when my children were expecting their own I had the same anxieties. Since the birth of my daughters second child – a wee boy with Down's syndrome, I have been on a very rapid and steep learning curve when it comes to accepting him, however I have managed this with no bother at all. He is absolutely delightful and a joy to be with. I honestly never thought I would be able to say this about a child with a learning disability, especially my own grandson but I'm proud to say he has made me a better person.
Geoff, a proud Grandad

Siblings

Breaking the news to your other children should be done in a supportive and loving environment. You may have to change the type of language and depth of information depending on the ages of your other children.

Keep in mind it is more important to welcome the new family member rather than focus on the syndrome. Children respond to honest, factual information which helps their understanding of the additional support needs that their new brother or sister has.

A siblings perspective

> I feel like having a sister with Down's syndrome is just like having an ordinary sister, to me it's no different.
> **Ty**

> Graeme is my life. I just don't know what I would do without him; in fact I'm sure he has made me who I am today. My brother is so important to me because I look up to him and we look out for each other. Like every nineteen year old he goes to the pub, socialises with friends and studies at college – I believe his social life is superior to mine and although we fight and argue, we still love each other very much.
> **Shona**

> The most important aspect that should be taken from my experiences with Laura, are that she will never be different to me, she is my best friend, knows how to cheer me up when I'm sad, to make me laugh and to make me cry. I love her and I will never let her be disadvantaged by her learning disability, life's far too short.
> **Sarah**

Caring for your baby

Your baby may appear a little floppy; this is due to low muscle tone and within a few days you will get used to handling your baby and finding what's comfortable for you both. Low muscle tone is common in babies with Down's syndrome and improves as they get older.

Feeding

Babies with Down's syndrome can be breastfed successfully which is a good way of giving extra protection against infection as well as bonding with your new baby. If bottle feeding is best for you and baby then make sure that feeding time is a time to get to know your baby.

Sometimes babies take a long time to feed because they have difficulty latching on to the breast or teat so try to keep baby awake by stroking his cheek, tickling the soles of his feet, unwrapping him or changing his nappy. Babies with Down's syndrome are more likely to have reflux. This occurs because the low muscle tone also affects their stomach muscles and they may vomit after feeds.

Different medicines can help, as can keeping the baby in a more upright position. All babies should be fed every four hours. If your baby displays pain or distress after feeding this may be an early sign of reflux and you should seek advice. While most children are fed orally some babies require to be partially or totally fed via a tube. This could be for a variety of reasons due to poor feeding skills or significant weight loss.

This can be upsetting for many parents but you will be shown how to administer and care for your child's feeding. When feeding your baby in this way always try to remember that he has the same emotional and social needs as other babies who are fed by the breast or the bottle.

It is important to consult with a speech and language therapist if your child experiences difficulty with feeding. You could ask your health visitor about how to do this or contact the Family Support Team.

Play and early stimulation

Playing with your baby will help his growth and development. Let your instincts guide you: cuddle, speak and sing to your baby when he is awake. Provide interesting sights and sounds e.g. cradle toys and mobiles across his cot within reach of his kicking feet. Turn bath time into play by tickling, blowing, kissing and singing.

Mouth play

Baby's first learn about the world through their mouths and tend to put all objects into their mouths (mouthing). However, some babies with Down's syndrome do not go through this important stage in their development automatically because they find oral sensations difficult or unpleasant. Encouraging 'mouthing' can ensure that your baby is exposed to the rich sensory world needed for normal development and can compensate for lack of oral sensations due to tube feeding.

- Use baby's own fingers and toes – the first mouth toy!
- Soft rubber toys with smooth surfaces
- Use a mirror to play with your child by blowing kisses etc.

Making mouth play fun and interesting plus plenty of touching and kissing on the face, cheeks and lips should ensure that your baby develops good oral skills and avoid the development of hyper sensitivity. Have fun together and enjoy your baby!

Wendy with daughter Grace

Health section

PCHR inserts

You should be given specialist extra pages for your child's health record book (the little red book). If you haven't got these then please ask your Health Visitor or contact us. These pages have been produced by the Down Syndrome Medical Interest Group (DSMIG UK) and give useful information about developmental milestones, health screening and special growth charts that your child's weight and measurements should be recorded on.

Speech development

Communication starts with eye contact, facial expressions, gestures, spoken language and tone of voice. It is important to talk, sing, smile and make faces at your baby to encourage this development.

Young babies often stick out their tongues and babies with Down's syndrome seem to do so more.

Whenever you notice his tongue sticking out, pop it back into his mouth with your finger and soon your baby will learn to do this for himself. Most babies with Down's syndrome have delayed speech and language development but nevertheless do learn to communicate effectively from an early age by talk, signing (MAKATON, Signalong). Speech and Language therapists* will suggest further ways of promoting development of communication and listening skills.

*See page 21 - The Professionals

Nina

Health checks

Try to attend all the health checks arranged for your baby. They give you confidence that your baby is healthy and developing well. They also make sure any possible problem is detected early, when treatment is likely to be more effective.

Some, but not all, babies with Down's syndrome can have one or more of the following health issues:

Heart

All babies with Down's syndrome should be screened in the early days after birth to check for heart problems. If you know before the birth that your baby will have Down's syndrome you may be offered a foetal heart scan while your baby is still in the womb. Some heart defects will require surgery which is normally done between four months and twelve months.

Vision

Babies with Down's syndrome should have an eye check at birth for cataracts or structural problems, then eye tests at around 18 months and again at 4 years. Should your child need more frequent checks, this will be recommended by the ophthalmologist.

Hearing

Initial hearing will be tested after birth and will then be tested again around 10 months by your health visitor who will refer your child to an audiologist* if required. Children with Down's syndrome are more likely to have ear infections, often known as 'glue ear', and some types of hearing loss because of the shape and structure of their ears and face. Do not attempt to clean your baby's ear by putting anything into the ear canal.

*See page 21 - The Professionals

Children with Down's syndrome may have an increased risk of developing thyroid problems. An overactive thyroid can make a person agitated while an underactive thyroid can make a person lethargic and slow. A simple blood test can be done to check the thyroid function. This should be carried out at birth and then annually or bi-annually throughout life.

Floppy windpipe

The trachea or windpipe in babies with Down's syndrome can be floppy which affects breathing and swallowing. This can lead to obstructive sleep apnoea (OSA) which wakes the child up. This can happen frequently through the night causing disruption to their sleep. Seek medical advice if concerned.

Further information

Further information on any of these health concerns can be obtained by contacting the Family Support Service.

As your baby grows

Remember that during the first year you are the most important person in your baby's life. Your attention and involvement will help your child's development more than anything else. These early years will be a learning experience for you as well as your child and the Family Support Service and Parent Contact Service at Down's Syndrome Scotland are able to support you.

As your baby grows he will be learning a great deal and you will have the support of many agencies to help him reach his potential. As your child develops you will experience some challenges and many rewards. It is important that you access the correct provision and services particularly at the transition stages of going to playgroup, nursery or starting school.

Future pregnancies

In order to find out if another pregnancy would result in the baby having Down's syndrome you should ask for the result of the chromosome analysis performed on the blood sample taken from your baby shortly after birth. The chances of having another child with Down's syndrome will depend upon the type that your baby has as well as the usual risk factor which is dependent on the age of the mother. There are three kinds of Down's syndrome: Trisomy 21 Down's syndrome (found in about 95% of cases), Translocation Down's syndrome and Mosaic Down's syndrome. If you have concerns you can be referred to a geneticist* for further advice.

Today children with Down's syndrome are healthier, more able and more integrated into the community than ever before. People with Down's syndrome now have many more opportunities to realise their potential. The negative attitudes towards disabilities are lessening because of a more inclusive society. It is important to remember that a baby with Down's syndrome is first and foremost a baby, a unique individual full of potential.

*See page 21 - The Professionals

The professionals

As a parent of a child with Down's syndrome you will come into contact with a wide range of professionals in relation to health, education and social services; many of whom visit all families with children and some who are specialists.

This section provides a brief summary of some of the professionals you may come into contact with. It is not intended to be comprehensive. Services will vary depending on where you live.

It may be down to you to chase up services or referrals. It pays to be assertive in these situations so don't give up! If you feel that you are not getting the support you need, remember we are here to support you so just give us a call. It is also worth remembering that you can also self-refer to many of these service, we can also help you with this.

All the Professionals you meet will have a background of training, knowledge and experience in assessment and planning for individuals with learning difficulties. They can help you solve specific problems and provide support to improve coping, caring and teaching skills.

Families are all different. The amount of contact you have with professionals will depend upon you and your child's needs. The Scottish Governments framework Getting it Right For Every Child (GIRFEC) should help you and the different professionals work together to achieve the best for your child.

It is always important to remember that you are the expert on your own children, professionals can suggest ways of helping your child; you are the person who will know what will suit your own family.

Overleaf is a list of the professional services you may come into contact with, do remember though this is only a guide as this can vary considerably for different local authorities.

Health care professionals

Audiologist
This is a doctor who runs services for people with hearing disorders.

If you are concerned about your child's hearing, make sure it is being fully investigated and ask your GP or health visitor about referral to Audiology.

Cardiologist
This is a doctor who specialises in disorders of the heart.

Paediatric cardiologists are based in Edinburgh and Glasgow, but out-patient clinics are held in other centres.

Community Learning Disability Nurses
Have specialist training in the field of learning disability and can offer advice, support, assessment and therapy.

Community Children's Paediatric Nurses
Who would help with heart problems pre and post operation if one was required and with feeding problems especially tube or gastrostomy feeding.

Dietician
Is an expert in nutrition who can give practical advice about eating healthily. Referrals are usually made through a GP.

General Practitioner (GP)
Gives general medical service and may not have specialist knowledge of Down's syndrome. They can make referrals to other professionals or organisations for you to receive specialist help.

Clinical Geneticist
Is a consultant specialising in genetic disorders; some parents who have children with Down's syndrome consult with them before they have more children. They can be contacted directly or through your GP.

Health Visitor
Is a nurse with specialist training in advising families with babies and young children under 5. They work in close consultation with the GP and will be responsible for your babies' developmental checks. They may also offer advice if they think that your child should be seen by a specialist.

Occupational Therapist (OT)
The OT looks at any activities your child may have difficulties with and can work with you on activities such as dressing and feeding, and general areas of co-ordination, muscle control, touch sensitivity and bodily awareness. They are also based within the social work department as well as in hospitals.

Paediatrician
Is a doctor specialising in the care of children. Initially you may meet the paediatrician in the maternity hospital and then the community paediatrician may be responsible for your child's follow up as they grow older. The community paediatrician also works closely with parents and colleagues in education and social work to ensure your child's developmental and medical needs are met.

Physiotherapist
Works with a child's development of posture and movement.

They can also help with advice on handling and positioning your baby and with any difficulties in achieving any particular stage of motor development. This role usually diminishes once a child is walking.

Speech and Language Therapist
Is concerned with communication. They can suggest ways of promoting the development of communication and listening skills as well as give advice on feeding and swallowing difficulties if they arise.

Education professionals

Educational Home Visitor/Home Teacher
Is a trained teacher attached to the local authority psychological services and works at home with your child to help their early cognitive abilities such as matching & sorting colours and shapes and the skills needed for reading, writing and number work. They will also work with you in planning an educational programme for your child.

Educational Psychologist
Will have knowledge and experience in the areas of child development, children with additional support needs and schools. They can give you advice about learning and behaviour as your child progresses through school, and will assess a child's additional support needs when required.e.g. school entry.

Learning Support Teacher
Teachers in mainstream schools who have a child with additional support needs in their class often have a learning support teacher to assist and advise them in developing teaching materials and methods, as well as teaching the pupil directly.

Learning Assistant/Teaching Assistant
These are additional staff allocated to children with additional support needs within classrooms or nursery settings to support them to access the learning environment.

Social services professionals

Social Worker
Can provide valuable support and counselling with regards to raising a child with additional support needs. They are also responsible for assessing your needs as a family for services such as respite, direct payments and other social services.

The benefit of hindsight

I see life like driving along a motorway. Some of us are fast and zoom past everyone else in the outside lane. Most of us travel at a steady speed in the middle lane, occasionally moving to the outside or inside lane when events require it.

Having a child with Down's syndrome I often find that I am forced to travel in the inside lane; this isn't a disaster because it gives me the opportunity to travel slower and enjoy the journey. I have more time to enjoy the scenery, see what my child is doing now and spend more time at the service stations- when we reach key developmental stages.

I know I will get to where everyone else is. It might just take me longer.

Nowadays we try and travel on dual carriageways. Everyone belongs together and by travelling with everyone else it shows people that difference isn't a bad thing and we've found most slow down for us and enjoy travelling alongside us, although we can always jump over to the fast lane too.

Written by a parent of a child with Down's syndrome.

Ryan

This booklet has been produced by Down's Syndrome Scotland. We are a national organisation who work to help people with Down's syndrome reach their full potential by providing information, services and support to them, their families, carers and professionals on all aspects relating to Down's syndrome.

We are here to support you and can arrange to visit you at home, speak to you on the phone, or by email. We can put you in touch with other parents either through our branches or with one of our parent contact volunteers, if you would like this. We hold a variety of information and also other organisation's contact details as well as our library resources, which we can share with you, if in doubt call us and ask.

Matthew and his brother

We have a Family Support Service Officer covering your local area, please do get in touch to see how we can support you.

Down's Syndrome Scotland is a registered charity in Scotland and we rely on donations to carry out the vital work we do in supporting families.

If you are interested in supporting us please visit **www.dsscotland.org.uk** or give us a call today.

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