



Congratulations on the birth of your baby

A Leaflet for New Parents



Congratulations and welcome!

Congratulations on the birth of your little one, and welcome to the DSA. We are a national organisation committed to improving quality of life for people who have Down's syndrome, promoting their right to be included on a full and equal basis with others.

We walk along life's journey with those who have Down's syndrome from birth to old age.

We are a membership organisation. The more members we have the stronger our voice and the greater our impact. To welcome you to our community, we offer you free membership for the first year. There is more information about membership at the end of this resource.

We hope this resource gives you the information you need at this stage. You can always call our Helpline on 0333 1212 300 with questions or for a chat. You can also email us: info@downs-syndrome.org.uk

Getting the news

Many parents find out their baby has Down's syndrome soon after their baby is born, but some new parents will already know that they are going to have a baby who has Down's syndrome.

Each parent will experience different feelings when they learn their baby has Down's syndrome. Parents have said it helps to try to focus on the here and now. As the days and weeks pass and you get to know your baby, you will see them as a unique, much loved and valued member of your family.

There is a lot of information on the internet about Down's syndrome. Some parents say that reading information from reliable sources lessened their worries about the future and helped to guide them. Other parents may find they prefer to leave reading about Down's syndrome until their baby is a little older and life has settled into more of a routine.

Remember we are here to listen and we would love to hear from you.

'I didn't worry too much about the immediate future, as having found the DSA when my daughter was 10 weeks old, I could see we would be good!'

What is Down's syndrome?

- Down's syndrome is a genetic condition caused by the presence of an extra chromosome in the baby's cells.
- Chromosomes are tiny particles which are present in every cell in every tissue of our bodies. Most people have two copies of all chromosomes but people who have Down's syndrome have three copies of chromosome 21. Down's syndrome is sometimes referred to as Trisomy 21, meaning three copies of chromosome 21.
- People who have Down's syndrome are born in every country in the world to parents of all ages and socio-economic backgrounds.
- Anyone can have a child who has Down's syndrome. Nothing done before or during pregnancy causes the condition.
- Every day in the UK, between one and two babies are born who have Down's syndrome, which means that one baby in 1000 has the condition.

What will my baby be like?

First and foremost, your baby has the same needs as all babies. They will eat, sleep and cry and will need love and cuddles like any baby. The most important thing that you need to know about Down's syndrome is that everyone with the condition is a unique individual.

As individuals, people who have Down's syndrome will inherit family characteristics and traits, and they will learn from the day-to-day interactions and activities they experience.

Children who have Down's syndrome generally need more time to reach developmental milestones. The ways in which the condition affects a person's development, learning and health varies widely. Although almost all people have a learning disability, the support a person needs as they grow up and throughout their lives will be different from person to person.

Should I be doing anything different with my baby?

In the early weeks and months enjoy and get to know your baby. Have fun talking to them, showing them the world, and responding to the many ways that they communicate with you.

Generally speaking, caring for a baby who has Down's syndrome is the same as caring for any newborn. As with all babies, enjoy them while they are little as they will grow up fast!

If there is anything on your mind, always seek advice from your health professional and you can also call us.



'The one piece of advice I would give is not only enjoy your baby, but look forward to enjoying your toddler, child, teenager and adult without always worrying about what you "should" be doing or what the future may bring.'



Feeding and breastfeeding

Almost all mothers who want to can breastfeed or provide breast milk for their baby. For some mothers breastfeeding is established easily, but others may find it takes a little more time, patience, and perseverance. Support should be available to help you if you want to breastfeed your child. Many hospitals employ a lactation consultant or have midwives with a particular interest in feeding.

For some babies, feeding gets easier as they grow older and they will be able to be fully breastfed. Some mothers choose not to breastfeed or find that because of their circumstances, breastfeeding is not right for them.

Some babies have health conditions which affect feeding. Babies with gastro-intestinal tract (GI tract) conditions who need an operation will not be allowed to feed at first and will get nutrients intravenously.

Some babies with heart conditions may be unable to feed immediately because they are tired or breathless. At such times, mothers can express breast milk by hand or

pump to build up their milk supply. Their milk can be given to their babies by naso-gastric tube when the babies are well enough.

With patience, and following surgery for any medical conditions, babies can often eventually fully breastfeed.

Your speech and language therapist will advise you on how to support the development of your baby's feeding skills, such as weaning, introducing new textures and tastes, chewing, drinking from a cup and drinking from a straw.

You will be referred to a specialist speech and language therapist as part of a multidisciplinary team if your baby has specific feeding needs, such as difficulties with sucking, swallowing and breathing.

There is information about biting, chewing and straw drinking at our website: downs-syndrome.org.uk/SpeechLanguageAndCommunication/

'My baby was tube fed for a few weeks until she learnt to breastfeed. She was breastfed for 22 months.'

Health

Babies and young children who have Down's syndrome have the same health needs as all children. They may have health issues that can affect any child. You should take your baby for routine health checks and immunisations in the usual way.

Some health issues occur more often in children who have Down's syndrome which is why some extra health checks are recommended.

Just over half of children who have Down's syndrome are born with a heart condition and ten percent are born with a bowel condition. Sometimes a baby will need an operation for these health conditions either soon after they are born or when they are older and stronger.

Children who have Down's syndrome may respond differently to infections and need special consideration which can be discussed with your healthcare team. You can read more about health checks in the **Personal Child Health Record (PCHR) Insert** for babies and children who have Down's syndrome produced by the Down Syndrome Medical Interest Group UK & Ireland (DSMIG) (fifth edition, 2020). Your healthcare team should have given you the insert.

'There is no single "right" set of approaches – every child who has Down's syndrome is an individual. Life's journey is long (and unexpected and wonderful) and learning takes place over many years. Just seek out the people who work well with your child, make them feel good about themselves and have the ability to see things from their perspective.'

It provides important information about a suggested schedule of health checks, developmental progress, advice about immunisation, feeding and growth. The insert includes growth charts specifically for children who have Down's syndrome because babies may gain weight or grow more slowly than average.

We send the PCHR insert to all new parents who join the DSA.

You can download the insert from dsmig.org.uk/information-resources/personal-child-health-record-pchr/

If you feel that your child hasn't had the right health checks, show the schedule to your GP, paediatrician and/or health visitor.

We can seek advice on your behalf from our medical advisers. Our medical advisers are unable to comment on individual test results but they will provide general information and guidance.

Support and advice about your child's development

Services for babies and young children who have Down's syndrome typically include speech and language therapy, physiotherapy and occupational therapy.

Other services may be involved, depending on your child's needs. Talk to your child's paediatrician, health visitor and/or GP about making the necessary referrals for you.

If you have questions about your child's development, ask for appointments to be brought forward.

You can read about the role of the speech and language therapist for babies and pre-school children who have Down's syndrome on our website.

If you have difficulties accessing services please contact us as we may be able to help.





What about family life?

The most important experiences for a child who has Down's syndrome come from being a member of a happy, loving and active family and from doing all the things that families do.

When you have a baby, it is important to try and find a balance that works for you and your family. In the early months and years, it is likely you will have some regular appointments with health professionals to discuss your child's health and development.

It's worth bearing in mind that, to some extent, all young children have to learn to fit in with what is going on around them and you will need to balance early learning activities with family life in a way that suits your family.



I wish I had known....

Here is what some parents of older children say they wish they had known when their baby who has Down's syndrome was born:

'I wish I'd known then that my baby would still be beautiful and would develop and do the things all babies do, albeit at a slower pace, and that he would teach me a lot of things.'

'A parent support group that I joined when my daughter was a year old was invaluable. I wish I had joined sooner but I was a bit in denial. I thought that I would just treat her the same as my other children and that would be fine but you do need help and the sooner the better really. Plus, I met lots of other people in similar circumstances and we were all able to help each other.'

'I can only describe how much joy my son has given me, although the first year was a challenge and there were some low points. My son is a happy, funny little boy who always makes people smile. Looking back, I shouldn't have worried that I could not cope or think I would not be a good parent to a child who has Down's syndrome. I shouldn't have worried so much!'

'I wish I'd made contact with the DSA's online group sooner as that would've been a great comfort. It probably would've helped to read some of the materials produced by DSA, as I have found them to be very positive and well written.'

'Wish I had known how proud I would be of her achievements.'

'Wish I had known she would attend mainstream primary school and make a difference to children's attitudes to disability.'

'I wish I had been told that it's ok to tell regular home-visiting therapists that we can't make the time that they are suggesting as it clashes with a local baby group in our own community where we would like to make friends.'

'I wish I'd known that my daughter would be, in many ways, a 'typical' funny, sassy, caring, grumpy, argumentative, wonderful teenager!'

'Thank you so much for your wonderful message. It was such a pleasure to speak to you yesterday, and your email today is so helpful I can't thank you enough! You have covered absolutely everything I was needing to get information about, and far more.'



Brothers and sisters

It's a good idea to talk to your other children about their new brother or sister who has Down's syndrome. As a parent, you are best placed to decide when to do this and how much information is appropriate to give your other children.

Much will depend on their age, their level of understanding and their curiosity. They may not understand or remember all the information, so follow their lead, keep listening and answer their questions.

Your children will follow your example. If you see Down's syndrome as just one aspect of your baby's life, your children will too. Your children may already have a classmate or know of someone in their school who has Down's syndrome.

Here are some quotes from brothers and sisters about their sibling who has Down's syndrome:

'She is a part of our family.'

'He is fun to play with.'

'We love using sign language because we can communicate with him.'

'We love celebrating her achievements.'

'She makes our lives better.'



*'It was a pleasure speaking with you today.
Thank you for your time and your advice - it's been very valuable.
Thank you for understanding and listening.'*

What do people who have Down's syndrome say about their lives?

If you would like to read about the lives of people who have Down's syndrome today, take a look at our website: downs-syndrome.org.uk/OurVoiceOurStories/

At the DSA we create an inclusive environment where everyone can participate and contribute. This is called inclusive participation. 'Our Voice' is a team of people who have Down's syndrome who work on projects and guide our work.



We are delighted to share some advice from 'Our Voice' members:

Bethan

'Make sure your baby is well looked after and that you bond with your new baby. If the baby has Down's syndrome they need to be well cared for. Just be yourself and have a good active life!'

James

'I would like new babies to have new toys so that they can play and learn.'

Lindsay

'If your baby has Down's syndrome, enjoy it and watch it grow up and if it needs help be there for it, especially during school.'

Sam

'I would like new babies to learn not to get up too early in the night and go into their parent's rooms! I don't want the parents to get too tired throughout the day because they lost a lot of sleep. I want them to spend a wonderful day with their baby. I want them to go to nursery to learn different things as well.'

Kate has the final word

'Being a person who has Down's syndrome makes me proud.'

'I am a person to make a difference to a lot of people. That's me.'

'We may find things difficult, everybody does. We should tell people about Down's syndrome – the more people, the better.'

'Being a person who has Down's syndrome I can do anything in life.'

'We may need help to find a job and work experiences through school and college. Thank goodness for education! We want to know everything.'

'Also, we can give talks to people. It is good to see people who have Down's syndrome achieving their dreams. That's my dream.'

Support, training and information

We have regular online pregnancy and baby support meetings. These are designed for parents of babies up to 18 months of age as well as expectant parents looking forward to welcoming their baby. By joining the group, you will have the opportunity to meet other parents as well as members of our team. You can ask questions on any topic.

Find out more here: downs-syndrome.org.uk/baby-and-pregnancy-support/

We offer a range of support meetings and webinars for parents and family members including Supporting Early Development from Birth to 4 years.

Visit our website (downs-syndrome.org.uk/training/) or email training@downs-syndrome.org.uk to find out more.

You might find it reassuring to read about the experiences of other families by joining our closed Facebook group for parents of children from birth to 11 years old: facebook.com/groups/DSABirthto11/

You can find resources to help development of speech, language and communication on our website: downs-syndrome.org.uk/SpeechLanguageAndCommunication/

You'll find 12 films by Movimento Down showing physical activities for babies guided by a physiotherapist on our YouTube channel: bit.ly/GrowingUpWithDownsSyndrome

The Early Support Developmental Journal for Babies and Children who have Down's syndrome can help families see and share their child's learning and development: bit.ly/DownsSyndromeDevelopmentJournalEarlySupport

Information resources change from time to time. Please call or email us to keep updated on the latest information resources and where to find them.



Who we are and how we can help you right now

If there is anything on your mind, please call our Information Team on **0333 1212 300** or email us on info@downs-syndrome.org.uk

We will share useful information for new members through regular emails.

You can join our online Baby and Pregnancy Support Group: downs-syndrome.org.uk/baby-and-pregnancy-support/

You can join our closed Facebook group for parents of children from birth to 11 years old: facebook.com/groups/DSABirthto11/

We can send you a new parent pack with a copy of the PCHR Insert for babies and children who have Down's syndrome. Just call us or email us to request one.

You can call our Benefits Adviser for advice about financial support on **0333 1212 300**.

We can seek advice for you from our medical advisers.

Membership

Free membership is available for new or expectant parents or carers of a baby who has Down's syndrome under 1 year of age.



Just go to downs-syndrome.org.uk/Membership/ to begin your journey with us.

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome. We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

Contact us

Down's Syndrome Association

Langdon Down Centre,
2a Langdon Park, Teddington,
Middlesex, TW11 9PS

t. 0333 1212 300

f. 020 8614 5127

e. info@downs-syndrome.org.uk

w. www.downs-syndrome.org.uk

Wales

e. wales@downs-syndrome.org.uk

Northern Ireland

e. enquiriesni@downs-syndrome.org.uk

FSC LOGO
POSITIONAL GUIDE
ONLY

