



**Down's Syndrome
Association**

A Registered Charity No. 1061474



Congratulations on the birth of your baby

A Leaflet for New Parents



'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.'

Getting the news

Many parents find out their baby has Down's syndrome soon after the birth, but some new parents will already know that they are going to have a baby with 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 and focus on the here and now. It's easy to get carried away with thinking about your baby's future. As the days and weeks pass, and you get to know your baby, you will begin to see them as a unique person with their own character.

There is a lot of information on the internet about Down's syndrome. It is tempting to want to read as widely as possible to ensure you feel you are armed with the facts. Some parents say that reading factual information from reliable sources lessened their worries about the future and helped to guide their expectations. 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 a routine.

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, that results in some level of learning disability and a range of physical characteristics.

The learning disability affects a child's ability to learn compared with other children of their age; it does not mean they cannot learn.

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 with 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 with Down's syndrome are born in every country in the world to parents of all races, religions and socio-economic backgrounds.

Anyone can have a child with Down's syndrome. Nothing done before or during pregnancy causes 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 other baby. The most important thing that you need to know about Down's syndrome is that everyone with the condition is a unique individual.

People with Down's syndrome have more in common with their families than with each other. Just like the rest of the population they will inherit their families' characteristics.

Children with Down's syndrome generally need more time to reach developmental milestones and they will need some additional support to learn new skills as well as extra help when they go to school. The way the condition affects a person's development, learning and health varies widely. The level of support a person with Down's syndrome needs as they grow up and throughout their lives will be different from



Every day in the UK, between one and two babies are born with Down's syndrome, which means that one baby in 1000 has the condition.



person to person.

Understandably, particularly if your new baby is a first child, you may be worried about whether something your baby is doing (or not doing) is because they have Down's syndrome rather than just because they are a baby. It is likely that whatever behaviour you are seeing in your baby has nothing to do with their condition. However, as a new parent it is natural to have some worries.

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

Should I be doing anything special or 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 their efforts to communicate with you, just like all parents do.

'I was informed before my baby was born that she would never breastfeed. It took some doing, a mixture between breastfeeding and expressed breastfeeding, but she fed for sure!'

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.

'I had always intended to breastfeed and when I was told after the birth that my daughter had Down's syndrome, I was even more determined that she would have the very best start in life that I could give her.'

Some babies will become better at feeding as they grow older and 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.

A few babies have medical problems 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; mothers of these babies 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, these babies can often fully breastfeed eventually.



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

Weaning – Babies with Down's syndrome should be introduced to solids at the same time and in the same way as other babies. It may take them a bit longer to co-ordinate the actions needed for eating solids.

- Introduce your child to finger foods as you would any other child, offering different textures and flavours.
- Give your child choices and let them touch and play with different foods.
- You may have to give your child a new food gradually and on a number of occasions before they will eat it.

Your child's speech and language therapist can give you advice about feeding.

Health

Babies and young children with Down's syndrome have the same health needs as any child. You should take your baby for routine health checks and immunisations in the usual way.

Babies with Down's syndrome can be fit and healthy and have no more health issues than any other child. However, we know they may have some additional health needs that could affect

Just over half of children with 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 issues either soon after they are born or when they are older and stronger.

their growth. They can pick up coughs more easily than other children and their narrow ear and nose passageways may become blocked more often.

It is a good thing that we know some health conditions are more common in babies and children with Down's syndrome because conditions can be screened for and treated.

The Down Syndrome Medical Interest Group UK and Ireland has produced this schedule of basic minimum health checks that all babies and children with Down's syndrome should receive as a matter of course.

The following are suggested ages for health checks. Check at any other time if there are parental or other concerns.

	Birth – 6 weeks	Special checks under 2 years	Preschool checks	School age
Thyroid blood tests	Newborn routine heel prick – blood spot test	From age 1 year thyroid function should be discussed annually using results of either <ul style="list-style-type: none"> • Annual fingerprick TSH test OR • 2 yearly thyroid blood tests, including thyroid antibodies 		
Eye checks	Newborn routine check including congenital cataract check	Age 18-24 months: Formal eye and vision examination including check for squint, and refraction for long or short sight	Age 4 years: Formal eye and vision examination including check for squint. Refraction and assessment of near and distant vision and visual acuity	Repeat vision test every 2 years, or more frequently if recommended by optometrist or ophthalmologist
Visual behaviour to be monitored at every review particularly in first year				
Hearing checks	Universal newborn hearing screen	Full audiological review by 10 months including hearing test and impedance check	Annual audiological review as before	2 yearly audiological review or more frequently if recommended
Growth monitoring	Length, weight and head circumference should be checked frequently and plotted on Down syndrome growth charts		Height and weight should be checked and plotted on Down syndrome growth charts at least annually while growing. (BMI checked if concern regarding overweight)	
Heart checks	By age 6 weeks, formal heart assessment including Echocardiogram	At all ages low threshold for reviewing heart status if signs or symptoms develop	From adolescence onwards as part of routine health checks listen to heart for signs of acquired heart disease	
Breathing checks	Enquire at every review for uneven breathing during sleep and poor quality sleep. Low threshold for further testing using sleep studies			
Blood checks	*Newborn blood test to check for abnormal blood film	If blood film is abnormal in first 6 weeks, follow up or repeat blood testing may be necessary until age 5		

Detailed recommendations for Medical Surveillance Essentials for children with Down syndrome can be found at www.dsmig.org.uk
 Reproduced from the Parent Held Child Record insert for babies born with Down syndrome with the kind permission of the Down Syndrome Medical Interest Group UK and Ireland.

*All newborns with Down's syndrome should receive a blood test and be examined for the possibility of transient leukaemia of Down's syndrome within three days of birth. If you have any questions about this please call our helpline.

If you feel that your child hasn't had the right health checks, show the list to your GP, Paediatrician and/or Health Visitor. The schedule of health checks is part of the Personal Child Health Record (PCHR) Insert for babies and children with Down's syndrome (2011 version).



Personal Child Health Record (PCHR) Insert for babies and children with Down's syndrome

In addition to information about health checks the Insert includes:

- advice about feeding, immunisation and growth
- your child's development (learning new skills)
- health issues
- growth charts (covering birth to 18 years)
- sources of additional help and advice.

Children with Down's syndrome tend to grow more slowly and are usually shorter than other children. This is why the PCHR Insert includes growth charts specifically for children with Down's syndrome. Sometimes parents of babies and young children call us because they have been told by a health professional that their child is failing to thrive. In some of these cases the children are actually doing fine, but alarm bells have been raised because the health professional is using a generic growth chart rather than the growth chart for children with Down's syndrome.

In common with all babies, babies with Down's syndrome lose up to 10% of their birth weight in the first three or four days. It may take them longer than other babies to regain this weight.



Early Support resources (see resources section of this booklet) have more information about services and how you can support your child's development.

Each child with Down's syndrome is different but generally their development is slower than that of other children. The Insert has information about the usual progress of development in children with Down's syndrome. We send a copy of the Insert to new parents who join the DSA (free of charge).

Support and advice about your child's development (Early Intervention)

You may have heard or read about 'Early Intervention' for children with Down's syndrome. This may sound a little daunting, but it needn't be. Early intervention is an umbrella term for a collection of services that can help babies and toddlers whose development is delayed. The focus of early intervention is on helping children learn skills that are usually learnt in the first three years of life.

Early intervention services for children with Down's syndrome typically include speech and language therapy, physiotherapy as well as home teaching programmes (sometimes called 'Portage'). What is available for families and how services are delivered will be different from place to place. Talk to your child's paediatrician, health visitor and/or GP about making the necessary referrals for you. Ideally, your child should be seen by:

- a speech & language therapist from around the age of six months. If your baby finds feeding and swallowing difficult, you may need to ask for an earlier appointment with a speech and language therapist
- a paediatric physiotherapist in the first three months of life and an occupational therapist when they are a little older.

Sometimes it will not be possible to see these professionals within the timescales suggested here. However, if you have any worries about how your child is getting on, ask for appointments to be brought forward.

The level of support from professionals will depend on the individual needs of your child. There are no hard and fast rules about how much support a child with Down's syndrome should receive. Early Support resources (see resources section of this booklet) have more information about services and how you can support your child's development.

What is life like for families?

On a day to day basis life for families with babies and young children with Down's syndrome brings with it the same hopes, joys, highs and lows as other families.

You might find it reassuring to read about the experiences of other families by joining the DSA Parent and Practitioner Group – Birth to 11 at www.facebook.com/groups/DSABirthto11/. There are a growing number of online support groups and blogs for and by parents. Our Information Team will give you more information about these.

In the early months and years, it is likely you will have many appointments with health professionals to discuss your child's health and development. It can be difficult to get the balance right so your needs and the needs of other family members are supported. With regular discussion about your child's development, what they can and can't do at a given age, it can be very easy to focus on comparing your child with other children and to forget that every child is unique.

'There is no single "right" set of approaches – every child with Down's syndrome is an individual and what works for some does not necessarily work for all. 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.'

'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.'



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

I wish I had known....

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

'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 with Down's syndrome. I shouldn't have worried so much!'

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

'I wish I'd made contact with the online group sooner, as that would've been a great comfort, and 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'd known that my daughter would be, in many ways, a 'typical' funny, sassy, caring, grumpy, argumentative, wonderful teenager!'



Brothers and sisters

It's fine to talk to your other children about their new brother or sister with Down's syndrome. As a parent, you are best placed to decide 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 treat Down's syndrome as just one aspect of your baby's life, your children will too. It is now very common for children with Down's syndrome to go to their local mainstream nursery and primary school. Your children may already have a classmate or know of someone in their school who has Down's syndrome.



There are a selection of life stories on our website:
www.downs-syndrome.org.uk/about/your-stories/

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

'She is just a part of our family.'

'He is fun to play with.'

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

'She makes our lives better.'

'We love celebrating her achievements.'

'We get excited when he laughs.'

'We enjoy going to the cinema with her.'

What is life like for people with Down's syndrome?

The quality of life, life expectancy and inclusion in the community for people with Down's syndrome have gradually been transformed as education and support have improved. There are now more opportunities for people with Down's syndrome to lead the lives they want to, however, we know we still have work to do to ensure that people with Down's syndrome have the same life chances the general population take for granted.

If you want to read about the lives of people with Down's syndrome today, take a look at the Down2Earth magazine. This is a magazine written by and for people with Down's syndrome. You can download past copies from the 'For People with Down's syndrome' section of our website.

'Here's a quote from my son from a few years ago on being praised for remembering something quite tricky – "I've got my magic brain in there". Yes he has a magic brain with lots of potential to be unlocked, but also a big personality and a huge, generous, loving heart with the ability to bring the best out in everyone he meets.'

Kate has the final word

“Being a person with 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 with 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 with Down’s syndrome achieving their dreams. That’s my dream.”



Who we are and how we can help you right now

The Down’s syndrome Association (DSA) is the only charity in England, Wales and Northern Ireland which 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.

- You can call **0333 1212 300** or email our Information Team on info@downs-syndrome.org.uk with any questions you have.
- We can put you in touch with other parents in your area.
- You can join our closed Facebook Group for parents and practitioners – Birth to 11 years www.facebook.com/groups/DSABirthto11
- We can send you a new parent pack with a copy of PCHR Insert for babies born with Down’s syndrome.
- We can give you free membership of the DSA during your baby’s first year.
- You can call our Benefits Advisers for advice about financial support on **0333 1212 300**.
- We can seek advice from our medical advisers if you have any questions about health issues.

‘I don’t think I have thought too much with worry about the immediate future, as having found the DSA when my daughter was 10 weeks old, I could see we would be good! ‘



Training

Early Development from birth to 4 years – we provide training about how to support children's early development. We explain what is known about how children with Down's syndrome learn and show how to support:

- communication, language and speech
- social development
- learning through play
- reading and number skills.

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

Resources

www.downs-syndrome.org.uk/news/growing-up-with-downs-syndrome-activities-for-young-children/

Growing Up with Down Syndrome – this series of 12 short films by Movimento Down shows physical activities for babies from birth to 3 months, 6 to 9 months, 9 to 12 months and for children older than 12 months, guided by a physiotherapist.

Early Support Information about Down syndrome – this is a guide for parents and carers with children and young people who have Down's syndrome.

www.downs-syndrome.org.uk/for-families-and-carers/growing-up/

In this guide you will find information on:

- Down's syndrome
- how Down's syndrome may affect you and your child
- where to go for further support and

information (references to social care and education law in this resource may be out of date – please contact the DSA for advice).

Early Support Developmental Journal for Babies and Children with Down's syndrome.

www.councilfordisabledchildren.org.uk/search/content/Early%20Support%20journals

The Journal can help families see and share their child's learning and development.



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

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www.dsactive.org



www.dsworkfit.org.uk



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