



**Down's Syndrome
Association**

A Registered Charity No. 1061474



Looking forward to your baby

Congratulations!



Congratulations! You are having a baby. You also know that your baby will be born with Down's syndrome or has a high chance of this.

All parents approach pregnancy and the birth of their baby differently. You may have been reading about babies and you may also have been reading about Down's syndrome. Things may still feel a bit strange as your baby isn't here yet. You might be wondering what your baby will be like and who they might take after?

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

'Take time to enjoy your pregnancy. Continue to prepare for your baby the same as you would have without the diagnosis.'

'I was 11 weeks pregnant when we discovered that our son would have Down's syndrome. It was a shock and it took a few weeks to adjust to the news. We concentrated on getting some basic information to discuss with our children. Needless to say he is gorgeous and our kids love the fact that's he looks just like them when they were babies. They are not really interested in chromosome counts!'

All of the quotations used in this publication are from parents, some of whom knew their baby had Down's syndrome before they were born.



Your baby will eat, sleep and cry and will need love and cuddles just like any other. In short, your baby will have the same needs as all babies.

Any general information you have read applies to your baby too. Anything you planned to do with your baby when they arrived before you found out they had Down's syndrome needn't change. Go ahead and do what you intended to do.

You do not need to be doing anything special or different (e.g. choice of toys, decoration of baby's room, intending to take your baby to the local new parent group).

Please call our Helpline if you would like to talk. Our information officers are here to help.

What will my baby be like?

You may not be surprised to hear that no one can answer this question. Your baby will inherit some of your characteristics, but just like any baby, they will be a unique person with their own personality.

Many parents talk about the joys of meeting their new baby and getting to know them in the first weeks and months. You will have fun talking to your baby and showing them the world.

Understandably, particularly if your 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. It's more likely that whatever behaviour you see is just your baby being a baby.



You can talk to your Health Visitor, Midwife or GP if you have any questions or concerns about your baby.



'First and foremost your baby is a child. That baby has great potential and sure, sometimes there might be challenges but the joy of each accomplishment cannot be put into words.'

'Take it one day at a time, don't worry about the future and don't overload yourself with information (which is what I did!). Also, realise every child is different (just like the population of children without Down's syndrome) and that every child is unique. One family's experiences may be different to yours.'



Feeding and breastfeeding

Almost all mothers who want to can breastfeed or provide breast milk for their baby. Sometimes breastfeeding is established easily with no more problems than with any other baby and sometimes breastfeeding can be harder and needs more time, patience and positive support.

Some babies will become better at feeding as they grow older and will be able to be fully breast fed. Some mothers choose not to breastfeed or find that because of their circumstances, breastfeeding is not right for them.

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

'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!'



A few babies have major medical problems which affect feeding. Babies with bowel blockages who need an operation will not be allowed to feed at first and will get nutrients intravenously.

Babies with serious 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. Once they have had surgery for their heart or bowel blockages some of these babies can breastfeed.



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.

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 helpful to read about the experiences of other families. There are a growing number of blogs by parents of babies and children with Down's syndrome.

Many parents who are going to have a baby say that talking to parents of babies and young children, particularly those who knew their baby would have Down's syndrome, really helped them.

Our information officers can put you in touch with other families and can guide you towards relevant blogs.



You can find lots of life stories, featuring children and adults, on our website www.downs-syndrome.org.uk/for-people-with-downs-syndrome/celebrating-our-lives

'I found meeting with other parents of young children very reassuring.'

'I can only describe how much joy my son has given me. Although the first year was a challenge and there were 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!'





Health – you and your baby

As with any pregnancy, it is important to look after your physical and mental wellbeing. Talk to your GP or Midwife if you have any questions about looking after yourself and keeping fit and healthy before your baby is born. NHS Choices website has lots of information about health and wellbeing during pregnancy www.nhs.uk. You can raise any worries you may have about your pregnancy, big or small, with the health professionals who are supporting you.



Babies with Down's syndrome can be fit and healthy and have no more health issues than any other child. However, we now know there are certain health conditions (e.g. heart and bowel) that are more common in babies with Down's syndrome. This knowledge means that screening will pick up and lead to treatment for these conditions. Some of these health conditions will be identified during pregnancy. You should be offered a detailed prenatal scan after your baby's diagnosis of Down's syndrome. Some health conditions will be picked up quite soon after a baby is born and in some cases babies may need corrective surgery.

Heart problems are common in people with Down's syndrome; roughly half of babies born with the condition will have a heart defect (half will not). Where children have a heart problem, it may be a relatively mild condition or may require surgery.





As a matter of course you will have a scan called a fetal echocardiography (ECHO). If a serious heart condition is detected in your baby, a paediatric cardiology specialist will be called upon to give advice and provide an action plan for care after your baby is born.

There are some heart conditions that will not be found until after a baby is born. Therefore, a postnatal ECHO and formal heart assessment is recommended for all babies born with Down's syndrome. This should happen before the baby is six weeks old or sooner if there are any signs or symptoms that they have a heart condition.



The Personal Child Health Record (PCHR) insert for babies born with Down's syndrome (2011 third edition Down Syndrome Medical Interest Group UK and Ireland www.dsmig.co.uk) contains information about health and development, health checks, immunisation, feeding and growth, Down's syndrome specific growth charts and sources of additional help and advice to help maintain the health and wellbeing of babies who have Down's syndrome. If you would like a PCHR insert, please contact us.





Birth planning

A birth plan is a record of what you would like to happen during your labour and after the birth. You can discuss this with the health professionals supporting you with your pregnancy.

Birth planning should include:

- Talking through the choices you have about your pregnancy (e.g. who you would like to have with you during labour, your options around pain relief, positions for labour and birth, where is the best place to have your baby).
- How you are supported and looked after during your pregnancy and labour – the Down Syndrome Medical Interest Group UK and Ireland recommends your pregnancy should be managed by an obstetrician led unit if you are carrying a baby with Down's syndrome.
- Your obstetrician may discuss with you the need for your baby's birth to be induced. This might be because your baby has some additional health needs and/or it may be because of your baby's growth. Planned induction ahead of the date the baby is due is fairly typical when a baby has Down's syndrome.
- Talking about how you would like to feed your baby and any support you may need to do so.
- Care for you and your baby after you give birth.



Looking ahead

The most important experiences for a child with Down's syndrome come from being a member of a happy, loving and active family. It's worth remembering that to some extent, all young children have to learn to fit in with what is going on around them.

In the early months and years, you may have many appointments with health professionals to talk about your child's health and development. You may have heard or read about 'Early Intervention' for children with Down's syndrome.

Early intervention is an umbrella term for a collection of services that can help babies and toddlers whose development is delayed. Early intervention services typically include speech and language therapy and 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.



'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.'

'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, who make them feel good about themselves.'





“Early Support Information about Down syndrome”, an online resource, provides information about services for your child and child development. This can be downloaded from our website www.downs-syndrome.org.uk/for-families-and-carers/education/early-years

We also recommend “Growing up with Down syndrome”, a series of short films on our website which show physical activities for babies www.downs-syndrome.org.uk/news/growing-up-with-downs-syndrome-activities-for-young-children

A father's experience:

‘After learning the news that Finley would have Down's syndrome we held a party – yes, that's right, a party! I knew many of my family and friends would find it difficult to approach the subject, we wanted to educate them as much as we could and let them know that we'd be proud of our son and we were excited about his arrival. I printed off basic information on Down's syndrome, photos, a definition of Trisomy 21, stories of children and adults with the condition and information about the future support we'd receive. We were lucky enough to know in advance of Finley's condition and we didn't want to waste a minute. The party saw people close to us come together and we were able to talk about Finley before he'd already arrived. A friend came up to me and admitted when he'd heard our news he'd thought Fin would be unable to communicate or go to school – how was he going to bring this up in conversation between two blokes? He read the information on the wall and came to me with a shake of the head 'I didn't have a clue! I can't wait to meet him now.'

Remember, there is no rush to be doing any of this before or immediately after your baby is born. In the first weeks and months you need to recover from giving birth and enjoy having your new baby around.



We hope all goes well with your pregnancy and that you are looking forward to meeting the new member of your family.

Best wishes from the DSA

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 successfully with Down's syndrome.



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- You can call our Helpline 0333 1212 300 or email our information team using info@downs-syndrome.org.uk. Our information officers are here to help.
- We can put you in touch with other parents in your area.
- We can send you a copy of the PCHR Insert for babies born with Down's syndrome and our new parent pack.
- 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.

We would like to express our gratitude to Dr Helen McGarry for her invaluable insight and contribution to the development and content of this resource.

We are also immensely grateful to Dr McGarry and all of the families who have generously provided photos of their children to be included in this resource.



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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www.langdondowncentre.org.uk

