



Down's syndrome

A Resource for Family and Friends



Congratulations, your family member or friend has just had a baby.

Welcome to the DSA and thank you for reading this resource.

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.

If you have any questions, you can call our Helpline (0333 1212 300) or email us (info@downs-syndrome.org.uk) and we will be very happy to assist.

How are your friends and relatives feeling?

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, the parent(s) will get to know their baby, and they will see them as a unique, much loved, valued member of the family. There is a lot of information online 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 would love to hear from you. If they wish to speak to someone, please direct the parent(s) to our Helpline.

What will the baby be like?

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

'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!'



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.

In the early weeks and months, the most important thing is for family and friends to enjoy and get to know the new baby. You can all 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!

Is there anything I should do?

It will come as no surprise that any new parent appreciates congratulations and being told how beautiful their baby is. Your family or friends are no different.

Every new parent feels differently. Try to find how they are feeling and go from there. It is important to take your cue from them; remember that what you are feeling may not be the same as the new parent(s).

If you are able to visit, take the chance to meet the new baby, get to know them and hold them. If the new parent(s) has/have other children, don't forget to make a fuss of them too so they don't feel left out.

You are welcome to call our Helpline or email us if you have any questions.

'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.'

Some information about Down's syndrome and what life is like today

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.

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





Who we are and how we can help

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 who have Down's syndrome, by campaigning for change and challenging discrimination.

Some new parents want to read information and have contact with other families quite soon after their baby is born, whilst others prefer to wait until their child is a little older. When you feel it is appropriate, let the new parent(s) know:

- They can contact us if they have any questions either via our Helpline or via email.
- We can put them in touch with other parents in their area. Call us on **0333 1212 300** to find the nearest support group or they can use the local group search facility on our website: downs-syndrome.org.uk/LocalSupportGroups/
- We can send them a new parent pack.
- They can have free membership of the DSA during their baby's first year.

Get involved

Take a look at our website to see the many different ways you can support our work: downs-syndrome.org.uk/get-involved/

Further information

New Parent section of DSA's website: downs-syndrome.org.uk/for-new-parents/

For more information, please contact us: **0333 1212 300**
info@downs-syndrome.org.uk

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

If you would like to learn about the lives of people who have Down's syndrome today, take a look at our website and our YouTube Channel:

Our Voice Our Stories archive: downs-syndrome.org.uk/OurVoiceOurStories/
DownsSyndromeAssoUK - YouTube

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

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

Contact us

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