



**Down's Syndrome
Association**

A Registered Charity No. 1061474



Down's Syndrome

A Leaflet for Friends and Family

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



This leaflet has been written to give you basic information about Down's syndrome, to provide some tips about supporting the new parents and to highlight further sources of information.

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 2 copies of all chromosomes, but people with Down's syndrome have three copies of chromosome 21, hence the medical name 'trisomy 21'.

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.

People with Down's syndrome are born in every country in the world to parents of all races, religions and socio-economic backgrounds. Having a child with Down's syndrome can happen to anyone.

What does it mean for my friend's/relative's baby?

First and foremost your friend's/relative's new baby has the same needs as all babies. They will eat sleep and cry and will need love and affection just 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.

The one constant is that every child with Down's syndrome will have a certain level of learning disability. The learning disability affects a child's ability to learn compared with other children of their age, it does not mean they cannot learn.

Children with Down's syndrome generally take longer to reach developmental milestones and they will need some additional support in the form of early intervention services as well as extra help when they go to school. The way the syndrome effects a person's development, learning and health varies widely. The level of support that a person with Down's syndrome needs as they grow up and throughout their lives will be different from person to person.

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

The quality of life, life expectancy and role in the community for people with Down's syndrome have gradually been transformed as education and support have improved. In fact the opportunities for people with Down's syndrome to lead the lives that they want have never been greater. However, we know that we still have work to do to ensure that people



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 family characteristics.



*It's OK to be sad and cry.
It's OK to be angry or worried.
It's OK to be happy too!*



with Down's syndrome have many of the same life chances that 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.



How are the new parents feeling?

People react differently to having a baby with Down's syndrome but most people find that the diagnosis of Down's syndrome comes as a shock. It's not what the new parents were expecting.

Because there is more information available about the condition and people are now better included in their communities, some new parents may come to terms with their baby's Down's syndrome quite quickly. However, many families take longer to adjust; it's usually a gradual process that takes place during the first few weeks and months as they get to know their new baby.



About half of new babies with Down's syndrome will be born with a heart condition. With more complex heart conditions the baby may need surgery quite soon after birth or in the first few months of life. In such cases the main worry for parents will be for the health of their new baby. They may not start to think about their baby having Down's syndrome until later on.

Accurate and up to date information about the condition can help to reduce some of the worries that parents have.

How you can help

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

If you are able to visit, take the chance to meet the new baby, get to know them and hold them. If the new parents 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.

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 with 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 parents 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
- we can send them a new parent pack
- they can have free membership of the DSA during their baby's first year



Contact us on **0333 1212 300** or info@downs-syndrome.org.uk





Get involved

Take a look at our website to see the many different ways you can support our work.

Further information

New Parent section of DSA's website

www.downs-syndrome.org.uk/for-new-parents/

Early Support information resource on Down's syndrome – covering from babies to young adults

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

You can also find stories on our website about people's lives.
www.downs-syndrome.org.uk

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



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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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