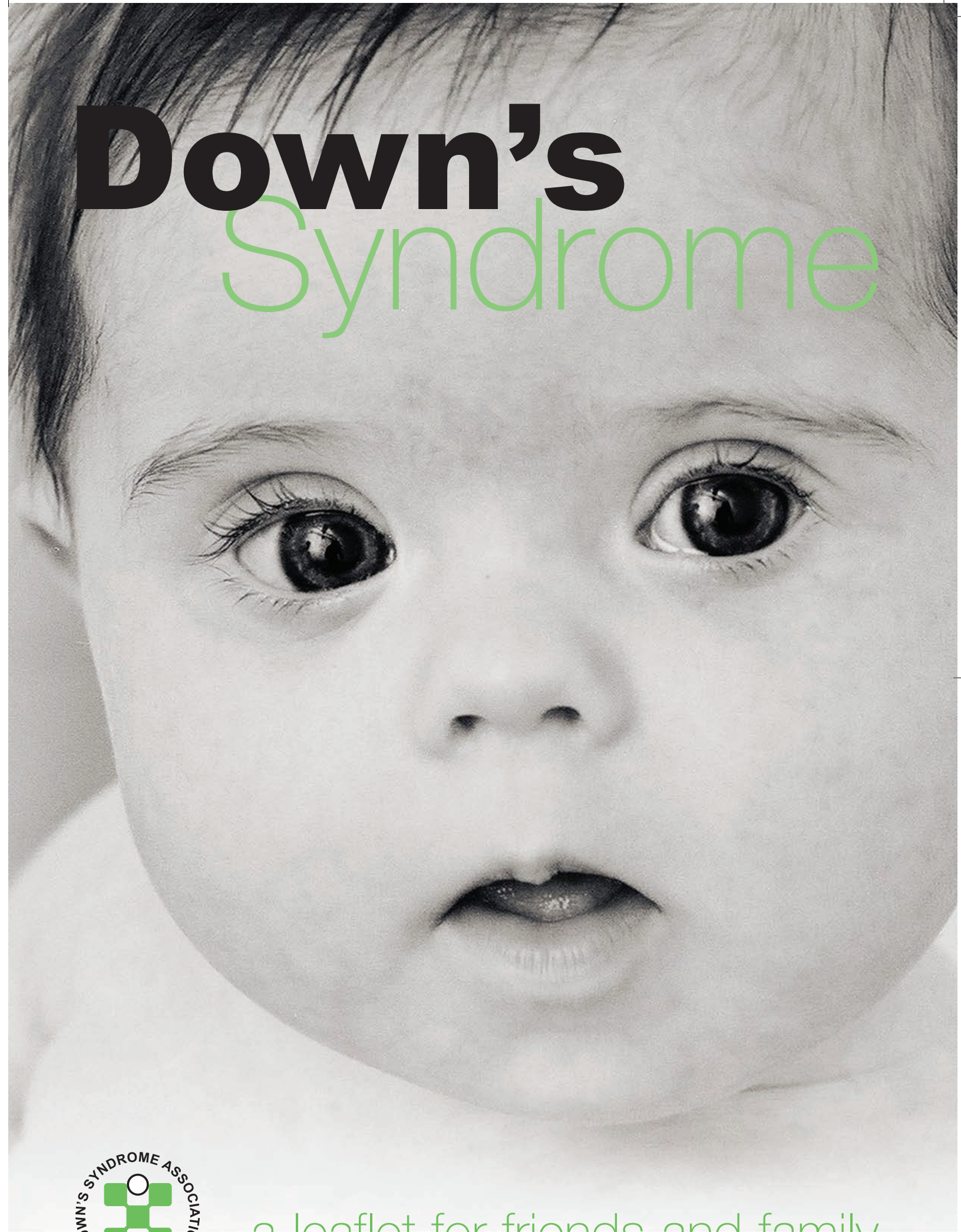


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Down's Syndrome



a leaflet for friends and family

Someone I love has had a baby with Down's syndrome

– I don't know what to say

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.

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

All people with Down's syndrome share some certain physical characteristics, though not every child with the condition has every characteristic. The baby will have inherited physical characteristics from his or her parents and will look much more like them than like any other person with Down's syndrome. The extra chromosome means that their baby will be slower to reach his or her developmental milestones and will have a certain degree of learning difficulty. However, the good news is that children with Down's syndrome do learn to walk and talk, ride a bike and read and write, in fact to do most of the things other children do. It's just that they will do them slower than other children. Initially it is important to remember that your friend/relative's baby is just

a baby! He will eat and sleep and cry like any other, and will need love and cuddles like any other.

Why are people sad when a baby is born with Down's syndrome?

People may be sad because they wanted their baby to be like most other babies. They may be scared that they will find it hard to look after their baby. They may not know anything about Down's syndrome.

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

What about me?

- It can be very difficult when a friend or family member has just had a baby with Down's syndrome.
- Not only do you have to deal with your own emotions and attitudes about a baby with Down's syndrome, but also your sadness for your friend or relative.
- Your support at this time will be very important to your friend or relative and can lead to a much stronger and deeper relationship.

What about the baby's parents?

- Remember the new parents are still the people that you know and love
- Most new parents go through a period of grieving for the dream

baby they imagined for nine months or more; the baby without Down's syndrome. The grief process may include denial, anger, bargaining, depression and acceptance.

- At the same time as grieving for the loss of their dream baby, our new parents develop feelings of love and joy for their actual baby. The baby who is the problem will become the solution.

What should I do?

- *Actions Speak Louder Than Words.* Actually being there and doing something will make more of an impact than any words you could say. Hug the parents, offer meals and baby-sitting, don't just say, *"Let me know if you need anything"*.
- Follow the lead of your friend or relative. Sometimes new parents need to talk about Down's syndrome; sometimes they need to talk about something totally different. Sometimes new parents need to be sad and cry; other times they want to remember the ordinary things of everyday life.
- Learn about Down's syndrome. Do not rely on outdated information or myths. Read some of the information produced by relevant organisations (DSA UK). Only pass the information on to your friend or relative if asked. You can contact us on **0333 121 2300** or go to **www.downs-syndrome.org.uk**

What should I say?

Avoid saying

- Anything that conveys pity:
 - "What a shame."*
 - "How sad."*
 - "Poor thing."*
- Statements like:
 - "It could be worse."*
 - "Down syndrome is the best disability to have."*

At this time nothing could be worse to the parent.

- Anything that puts blame on the parents:
 - "What do you expect at your age."*
 - "Why didn't you have an amnio?"*
- Explanations for why this happened:
 - "It only happens to special people."*
- Anything that conveys sainthood:
 - "I couldn't handle it."*
 - "You must be a saint."*

Parents like to hear:

- Congratulations
- Compliments
 - "She's a wonderful baby."*
 - "What a beautiful baby."*
- Noticing similarities between the parents and child
 - "Gosh, I can see his dad in him!"*
 - "She's got your beautiful eyes."*

- Your acceptance of the baby
 - "Can I hold him?"*

- Acknowledgement of their grief
 - "I know I can't take the hurt away but I wish I could."*
 - "I can't imagine what your family is going through, I don't understand, but you have my support."*

Be available; if you avoid your friend or relative you will miss out on getting to know an exceptional person... the new baby.

What does the DSA offer?

- We provide advice, support and information for people with Down's syndrome, their families and carers, as well as being a resource for interested professionals.
- We work to improve knowledge and understanding of the condition amongst all our audiences including the general public, government services and a wide range of other interested groups.
- We champion the rights of people with Down's syndrome, campaigning for change and challenging discrimination where we find it.

Information Services

- Our website – **www.downs-syndrome.org.uk** – is a highly respected international source of information about the condition.

- Our telephone helpline and email advice service staffed by experienced and friendly Information Officers is available from Monday to Friday between 10am and 4pm. Outside these times an emergency service operates – the helpline number will give details.

- A range of resources and publications for families, carers, adults with Down's syndrome and professionals covering many aspects of living with Down's syndrome.

- We produce a magazine for members three times a year.

- National office hosts a reference library of books and videos (access by appointment only).

- We offer conferences and training sessions for parents, carers and professionals.

Local Support

We can put you or the baby's parents in touch with local parent support groups in your area. Give us a call **0333 121 2300** to find the closest one to you.

