The Down Syndrome Association Gauteng

DOWN SYNDROME

A GUIDE FOR FAMILY AND FRIENDS

CONGRATULATIONS, YOUR FAMILY MEMBER | FRIEND HAS JUST HAD A BABY

This leaflet provides basic information about Down syndrome and provides guidelines on supporting the new parents along with further sources of information.

WHAT IS DOWN SYNDROME?

Down 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 syndrome have three copies of chromosome 21, hence the medical name "Trisomy 21".

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

Having a child with Down syndrome can happen to anyone.

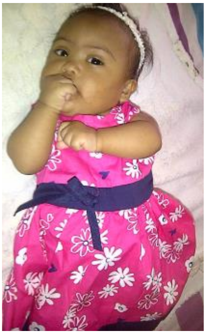
Every day, between one and two babies are born somewhere in the world, which means that one baby in 1000 has the condition.

WHAT DOES IT MEAN FOR MY FRIEND’S | RELATIVE’S BABY?

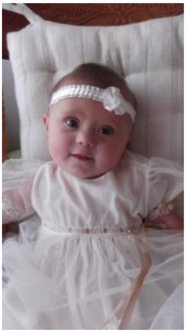
First and foremost, your friend’s | relative’s new baby has the same needs as all babies. They will eat sleep and cry and will need love and affection just like any other baby.

The most important thing that you need to know about Down syndrome is that everyone with the condition is a unique individual.

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



The one constant is that every child with Down 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.

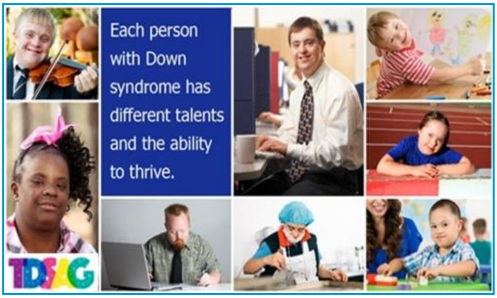


Children with Down syndrome generally take longer to reach developmental milestones and they will need some additional support in the form of early intervention services as well as extra help when they go to school.

The way the condition effects a person’s development, learning and health varies widely. The level of support that a person with Down 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 SYNDROME?

The quality of life, life expectancy and role in the community for people with Down syndrome has gradually transformed as education and support have improved. In fact, the opportunities for people with Down syndrome to lead the lives that they want has never been greater.



However, we know that there is still much work to do to ensure that people with Down syndrome have many of the same life chances that the general population take for granted.

HOW ARE THE NEW PARENTS FEELING?

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

It is OK to be sad and cry.

It is OK to be angry and worried.

It is OK to be happy too!

Accurate and up to date information about the condition can help to reduce some of the worries that parents have. 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 the fact that their baby was born with Down syndrome, quite quickly. However, many families take longer to adjust. In many instances, it is 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 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 syndrome until later on.

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 their new baby, get to know baby and hold baby. If the new parents have other children, please do not forget to make a fuss of them too as otherwise, they may feel left out.

WHO WE ARE AND HOW WE CAN HELP!

The Down Syndrome Association Gauteng (TDSAG) provides information and support on all aspects of living with Down syndrome. We also work to champion the rights of people with Down 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, while others, prefer to wait until their child is a little older.

- When you feel it is appropriate, please let the new parents know:
- They can make contact with us for any questions they have.
- We will provide them with Early-Intervention (EI) parent support packs and if needed, counselling.
- We will refer them to a TDSAG Support Group nearest to their place of residence.
- We will refer them for monthly health checks and therapy intervention at a hospital nearest to their place of residence.
- They will receive free membership of TDSAG and support.

GET INVOLVED!

Please take a look at our website to find different ways on how you can support our work.

A wide range of Down syndrome support documents and publications can be downloaded free of charge from our website.

TDSAG CONTACT DETAILS

The DSA Gauteng Office:

Telephone: 011 615-4180
E-mail: marlene.dsag@megaweb.co.za

For Parents who prefer to speak to someone in their own home language:

Saul Sibanda – TDSAG Outreach Co-ordination Manager:

Cell: 076 916-9814
E-mail: saul.dsag@vodamail.co.za