

Remember to celebrate the birth of the new baby!

Although it may seem that the new parents are going through a difficult and sad time they still do have a baby.

Most new parents will go through various stages such as grief, anger, denial, bargaining and acceptance. Not necessarily in that order. Although the new parents may be grieving for the loss of the baby they were expecting, they still do develop feelings of love for their baby.

Don't, no matter what ignore the parents or the baby and always treat the baby as you would any other.



What to Say and How to Talk about Down syndrome

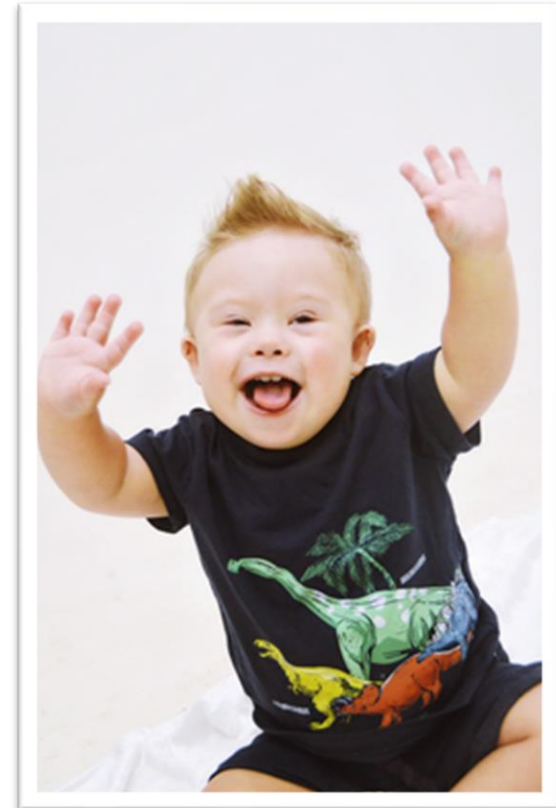
This brochure has been put together for families and friends of people with Down syndrome.

The purpose is to guide you into using the correct terminology, dispel myths and answer questions that you may have.



The Down Syndrome Association Gauteng

**A guide on Down syndrome
for family members, friends and
interested persons**



TERMINOLOGY

Always refer to a person with Down syndrome as the **person first** and not the disability first. E.g. “that Downs baby” or...”my downie”... People with Down syndrome are **people first** and need to be called by their name or with reference to” a person with Down syndrome”.

There is no **‘s’** at the end of Down. Recent practice is not to capitalize the s in syndrome.

Developmentally delayed, intellectually disabled/challenged and Learning disability are terms also used and accepted. Referring to a person as being retarded or a “Mongol” is certainly **not** acceptable.

Many parents of children with Down syndrome see their child as normal, therefore comparing them to normal children implies that children with Down syndrome are less than normal or abnormal. It is better to call so called “normal” children typical developing or non-disabled children.

INFORMATION

Down syndrome is a condition and not an illness, therefore people with Down syndrome do not *‘suffer’* from it.

We are often asked what the grade or severity of Down syndrome is in a specific person. A person either has Down syndrome or does not have it but *mild/severe* Down syndrome does not exist.

Although the chances of a woman having a child with Down syndrome increases over the age of 35 years, there are far more children with Down syndrome being born to younger mothers.

It is nothing that either parent did before or during the pregnancy that caused Down syndrome.

A baby with Down syndrome has inherited the genetic ‘make up’ from his parents. This means although they have Down syndrome and many of the characteristics they will still look like their family, e.g. Hair and eye colour.

HEALTH CARE

Babies with Down syndrome have increased risk of having some congenital anomalies and developing certain medical problems, most of which are now correctable by surgery.

Therefore, it is vital for babies and children to go for regular check-ups to physicians who are knowledgeable and pro-active regarding Down syndrome.

Families and friends of children with Down syndrome should know that just like with any other children, children with Down syndrome benefit largely from loving and stimulating environments such as family homes.

The baby with Down syndrome has the same needs as any other baby. They need to be loved and cared for.

Every child is different and the rate at which they learn or grow differs. Factors such as muscle tone and general health may affect the rate of development.

DOWN SYNDROME - WHAT TO SAY AND WHAT NOT TO SAY

When speaking about issues relating to Down syndrome in a way that is both factually accurate and inoffensive to the general public, including people with Down syndrome and their families, please consider the table below.

We are sure you share our concerns so please take a minute to check that your copy is in line with the following language guidelines and that you are not perpetuating any myths about the condition.

DO NOT SAY	DO SAY
Mongol	Person baby child with Down syndrome
Suffers from OR is a victim of Down syndrome	Has Down syndrome
A Downs baby person child	A person baby child with Down syndrome or who has Down syndrome
Retarded mentally handicapped backward	Learning disability
Disease illness handicap	Condition OR genetic condition
Downs (as an abbreviation)	DS (as an abbreviation if necessary)

MYTHS	FACTS
People with Down syndrome do not live very long.	Today, people with Down syndrome can look forward to a long life.
Only older mothers have babies with Down syndrome.	Although, older mothers have a higher individual chance of having a baby with Down syndrome, more are born to younger mothers, reflecting the higher birth rate in this age group.
People with Down syndrome cannot achieve normal life goals.	With the right support, then can. The vast majority of people with Down syndrome learn to walk and talk, and many are now attending mainstream schools, passing exams and living full, semi-independent adult lives.
People with Down syndrome all look the same.	There are certain physical characteristics that can occur. People with Down syndrome can have all of them or none. A person with Down syndrome looks more like his or her close family than someone else with the condition.
People with Down syndrome are always happy and affectionate.	We are all individuals and people with Down syndrome are no different to anyone else in their character traits and varying moods.