

## USEFUL INFORMATION FOR DOCTORS AND HEALTH CARE PRACTITIONERS

*We have put this useful brochure together for your benefit. We are the proud parents of children with Down syndrome and have been on the receiving end of having the news broken to us. Too often parents are distraught by this news, we believe that by informing the parents the right way one can minimise the trauma and improve the chances of everyone involved to a better quality of life.*

*These are simple guidelines for you to follow and they can make a big difference. If you are informed on the potential of and opportunities for people with Down syndrome, you can convey a more optimistic vision to the parents. This may in the end be the most determining factor of the child's life, as parents will bring him/her up as a child with a future.*

*This will also be useful with a prenatal diagnosis of Down syndrome and for breaking the news to parents of children with other intellectual / inherited disorders.*

## DOWN SYNDROME SOUTH AFRICA

### MISSION OF DOWN SYNDROME SOUTH AFRICA

Down Syndrome South Africa (DSSA) is committed to finding ways to improve the quality of life of all persons with Down syndrome, promoting the fact that they have the right to live with independence, dignity and security as valued adults and full citizens in our society. DSSA endeavours to empower families through dissemination of information, encourages research in the fields of early intervention, education, medical aspects and employment. DSSA's ongoing mission is to bring South Africa in line with world trends in the field of Down syndrome and to be leaders in some aspects and to see to it that civil rights stipulated by UN conventions on the rights of disabled adults and children are recognised and honoured in all spheres.

#### CONTACT DETAILS:

##### WEBSITE:

[www.downsyndrome.org.za](http://www.downsyndrome.org.za)

##### NATIONAL OFFICE:

0861-369 672 (0861-DOWNSA)

Email: [dssaoffice@icon.co.za](mailto:dssaoffice@icon.co.za)

## BREAKING THE NEWS

### HOW TO TELL PARENTS ABOUT THEIR CHILD'S DIAGNOSIS OF DOWN SYNDROME



*“It's time to celebrate the birth of a new baby... who needs to be loved and to be nurtured like any other baby...who needs to be held and cared for...who needs to go home with us.”*

**A guide for Health Care Practitioners  
by Down Syndrome South Africa**

#### ALWAYS REMEMBER TO...

- Celebrate to birth of the baby with the family
- Use people-first language at all times e.g. “Your baby has Down Syndrome” NOT “She is a Downs baby”.



- Use the baby's given name.
- The use of the word Mongoloid is NOT acceptable, ever!
- Encouragement of placement into institutions is not acceptable.
- Encourage nurturing and if there are no immediate medical concerns, the baby needs to go home as soon as possible. Her needs for the most part are the same as those of any other infant.
- Down syndrome is not a disease to be cured however you are not exempt from your responsibility to care.
- Children with Down syndrome are typically

healthy children.

- A suspected or confirmed diagnosis should be given to parent as soon as possible and in private.
- The baby should be held by the parents or by the physician when the diagnosis is discussed.
- Both parents should be present for the initial diagnosis. In the case of a single mother, her significant other, birth coach or family member should be with her for support.
- There are many different ways to understand, accept and cope with information that was not expected. Don't make judgements.
- Encourage breastfeeding and suggest the staff assist her or contact a lactation consultant or

speech therapist.

- Plan follow up visits to discuss other common medical concerns as parents are often overwhelmed upon the initial diagnosis.
- Accentuate the positives, e.g. "She may learn at a different rate" INSTEAD OF " She may never read:
- Ask the family if you may contact the local Down Syndrome Association in order to have a resource/support parent visit the new family as soon as possible.

**When breaking the news to the family, you want to make sure you get it right the first time, as your words will have a lifelong impact...impact...impact.....impact.....You could start by saying:**

*"Congratulations on the birth of your little girl/boy (use baby's name). I have some information about (use baby's name) that I need to share with you.. It looks as though she/he may have Down syndrome. We'll do some tests and let you know the results as soon as possible. Your baby is doing just great and would benefit if you could start nursing her/him as soon as possible. I would encourage you to have the baby "room in" with you during your stay in the hospital. This would be the best thing for both you and the baby. There are great resources available on Down syndrome. Talking to other parents and getting information also helps. Would you like me to make contact with the local Downs syndrome Association for you? They can drop off or send some information and perhaps have a chat with you. The up-to-date information you receive from them can be very helpful."*

The parents are probably going to be very shocked and upset by the news and will be asking a lot of questions. Try to follow the guidelines when giving them information on Down syndrome. Tell them that you would prefer to make contact with us so that we can give them more valuable information and emotional support.



**DON'T LET YOUR WORLD BE TURNED UP SIDE DOWN**

**OUR CHILDREN CAN AND WILL LEARN — WITH OUR HELP WE CAN SHOW YOU HOW**

**Contact your nearest Down Syndrome Association now for assistance or National office at 0861-DOWNSA (369-672)**