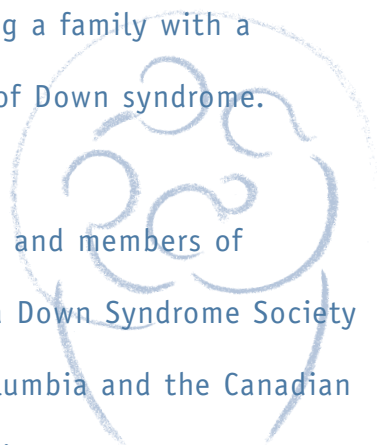


Dear Pediatricians, Family Physicians
and Health Care Practitioners,

We are proud parents of children with
Down syndrome. We have put together
some guiding principles we believe will
be helpful to you when you are supporting
a family who has given birth to a child
with Down syndrome. This may also be
useful in counselling a family with a
prenatal diagnosis of Down syndrome.

From proud families and members of
The Greater Victoria Down Syndrome Society
Victoria, British Columbia and the Canadian
Down Syndrome Society.



Acknowledgements

For information about Down syndrome,
workshops on "Sharing the News" or other issues,
parent support and to obtain more copies of
this brochure contact:



The Canadian Down Syndrome Society
811 - 14 Street N.W., Calgary, Alberta, Canada T2N 2A4
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Toll-free 1 800 883 5608
Email: dsinfo@cdss.ca Website: www.cdss.ca

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Sharing the
News



How to tell parents about
their child's diagnosis
of Down syndrome

celebrate the birth of our baby with us... our baby needs to go home with us as soon as possible and be loved and nurtured like any other baby...your responsibility to care...the baby needs to be held by the parents or by the physician when the diagnosis is discussed... many different ways to understand, accept and cope...encourage breastfeeding ...plan follow-up visits... accentuate the positives... celebrate the birth of our baby with us... our baby needs to go home with us as soon as possible and be loved and nurtured like any other baby...your responsibility to care...the baby needs to be held by the parents or by the physician when the diagnosis is discussed...many

Your first words to a family have a lifelong impact.

Please remember...

You could say:

- To celebrate the 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 word mongoloid is not acceptable, ever!
- Encouragement of institutionalization is not acceptable.
- To 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 parents as soon as possible 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 any judgements.
- Encourage breastfeeding and suggest that the mother talk to a lactation consultant.
- 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 chapter in order to have a resource parent visit the new family as soon as possible.

"*Congratulations on the birth of your little girl (use baby's name). I have some information about her that I need to share with you. It looks as though she may have Down syndrome. We'll do some tests and let you know the results as soon as possible. For now I just want you to know she seems to be doing great. I encourage you while you are in the hospital to have her room in with you as much as possible. It's important for you and for her. Please start nursing her as soon as possible. It's the best thing for both of you. There are some great resources available for you about nursing a baby with Down syndrome. A lactation consultant is available to help you get started. Parents tell us that meeting another family was probably their most valuable experience. Would you like me to have another parent/couple who have a young child with Down syndrome come by to meet you? I have access to information on associations of parents who have children with Down syndrome, as well as current research and information. The social worker here at the hospital will also be able to help you access resources. Some couples prefer a private room. We'll try our best to accommodate your needs - just let us know. One of the best things I can recommend is for you to join the Down Syndrome Society in your area. The up-to-date information you receive will be very helpful!*"



Raelene



Marc



Ann, Martin and baby Zola



Michael