

# DELIVERING A DIAGNOSIS OF DOWN SYNDROME

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## POSTNATAL

1. The person to communicate the Down syndrome diagnosis should be a physician.
2. Obstetricians, neonatologists and pediatricians should coordinate their messages.
3. The diagnosis should be delivered as soon as a physician suspects the diagnosis, but only after the mother is settled.
4. Parents should receive the news together, in a private setting.
5. The physician should first congratulate the parents on the birth of their child and not forget to talk about the positive aspects of Down syndrome. They should not begin the conversation by saying, "I'm sorry."
6. Health care professionals should keep their personal opinions to themselves.
7. Mothers should be provided with up-to-date printed materials – at a minimum, a bibliography listing the most current resources for new parents.
8. Parents should be put in touch with other families who have children with Down syndrome.
9. After the diagnosis or suspicion is shared, parents should be offered a private hospital room.
10. All physicians should educate themselves about the educational and social potentials of children with Down syndrome.



## PRENATAL

1. Results from the prenatal screening should be clearly explained as a risk assessment, not as a "positive" or "negative" result.
2. Results from the amniocentesis or CVS should, whenever possible, be delivered in person, with both parents present.
3. Sensitive language should be used when delivering a diagnosis of Down syndrome.
4. If obstetricians rely on genetic counselors or other specialists to explain Down syndrome, sensitive, accurate, and consistent messages must be conveyed.
5. Physicians should discuss all reasons for prenatal diagnosis including reassurance, advance awareness before delivery of the diagnosis of Down syndrome, adoption, as well as pregnancy termination.
6. Up-to-date information on Down syndrome should be available.
7. Contact with local Down syndrome support groups should be offered, if desired.