



## Presenting the Diagnosis

- Give it in person, sooner, rather than later
- Tell both parents together, if possible
- If you are working with a single mother, be sure she has a support person present
- Have the baby in the room when discussing the diagnosis and any physical features which indicate a diagnosis of Down syndrome
- Ask the parents what information would be helpful to them. Many hospitals have the Down Syndrome Association Hospital Packet.
- Ask the parents if they would like to visit with experienced parents. By calling the Down Syndrome Association of Greater St. Louis, the New Parent Support Coordinator can speak with the family and connect them with other families.
- Do not express an opinion about the parent's situation
- Provide referrals to the Down Syndrome Association of Greater St. Louis and early intervention programs.
- Avoid being predictive about the child's future
- Be sure to visit with the parents again after the initial discussion to see if they have any follow up questions

## Special Considerations

- Parents will ALWAYS remember the way they were informed their child has Down syndrome.
- Parents may be too overwhelmed to absorb the information provided at the time of the diagnosis.
- What you don't say, can be as important as what you do say. Don't forget to say CONGRATULATIONS!
- Avoid generalizations such as people with Down syndrome are always so happy.



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- Parents report being offended by statements such as “God only gives special children to special people”.
- Be well read on current Down syndrome best practices.
- Use “People First” language. Refer to their child as a baby with Down syndrome, NOT a Down’s Baby as that puts the diagnosis before the person.
- Be sure the entire team of health care professionals working with the new parents understands consistent messaging is important.
- Please provide current and accurate information on Down syndrome. It is not recommended that you provide any publications 7 years or older.
- Make sure ALL health care professionals on the Labor/Delivery floor know where this information is housed so they can access it easily.
- It is extremely helpful for new parents to meet other parents of children who have Down syndrome.
- Couples may respond differently to hearing the news their baby has Down syndrome. Following the best practices outlined here will help you in your supporting role during what may be a difficult time.