

## Friends & Relatives: What to Say, Not to Say

Sometimes you may not know the right thing to say or what you do say, is in fact, the wrong thing. We would like to give some suggestions about what language to use when a baby receives a pre-natal or post-natal diagnosis of Down syndrome.

The following suggestions are based upon the input of many parents of children with Down syndrome.

### Things NOT to say

These are the things that parents have said really upset or angered them:

**"I'm sorry" or any form of pity.** Pity is not what new parents want or need. What they need is love and acceptance of their new baby.

**"God gives special children to special parents" or any variation.** The new parents probably don't feel very special right now. Also, some parents may be a little mad at God. Trying to make them feel better with words like these might be appreciated by some parents and not by others. It is best to avoid this.

**"They're such loving children."** This is a stereotype of children with Down syndrome and demonstrates that you really don't know much about Down syndrome.

**"Do they know how serious it is?" or "How retarded will s/he be?" or any variation thereof.** Again, this is a demonstration of a lack of knowledge about Down syndrome. Some parents may be angry and want to reply with, "How serious is it? Well, every single cell in his body has an extra chromosome... is that serious enough?" It is impossible to project the developmental future of even a typical baby/child 10 or 20 years into the future, you shouldn't ask about their child with Down syndrome. ***And wipe the 'R-word' out of your vocabulary!***

**"You are handling this better than I could."** This is an invitation for the new parents to say something like, "No, you would be wonderful." Suddenly, the conversation has switched to you instead of the parents and their new

baby. Plus, you don't really know how the new parents are handling it, do you?

**"That could have happened to me!"** This is usually followed by sharing a personal story of a false positive screening test during a pregnancy and again, the conversation has now turned its focus on you instead of the parents and new baby. Whatever you may have felt during the waiting time after your false positive is NOTHING compared to what they're going through. Don't even mention it.

**"Did you know ahead of time?"** This seems like an innocuous question but the underlying question can be construed as "Why didn't you terminate the pregnancy?"

**"You really didn't know?"** This suggests that the parents would have done something differently, or should have (terminated). They should not be made to feel judged at this time. If they didn't have a prenatal diagnosis, they may have chosen not to have testing, and were at peace with their decision to accept whatever might happen as a result.

**"Well, at your age, you had to expect it. Right?"** A couple's decision about prenatal screening, testing and what to do with the information that it yields is very personal. MYOB-Mind Your Own Business.

**"But you're not old enough -- I thought this only happened to older mothers?"** More babies with Down syndrome are born to mothers under the age of 35 (the age over which prenatal screening is recommended) because more women under that age are having babies and are not being screened.

In our group, we have mothers that were in their teens and early 20s when their babies with Down syndrome were born.

**"Why did you let this happen?"** Again, this presumes that the parents would have chosen to terminate the pregnancy and also that their child is not a blessing to the family. Or it implies that something the mother may have done during pregnancy may have caused the genetic defect (it didn't).

**"Maybe s/he will grow out of it."** This is not within the realm of possibility and not a helpful or supportive comment.

**"You're not going to have any more children, are you?"** A couple's decision about how many more children to have may or may not be influenced by their child's diagnosis. Now is not the time to talk about it.

**"I saw this on a soap opera once where a character had a baby with Down syndrome and..."** Totally irrelevant, especially if it includes horror stories of intense medical issues with the baby on the show.

**"Well, at least he'll be the smartest person in [insert state name here]!"** This is more of a statement of the superiority of wherever you're from versus wherever this family currently lives. A very provincial attitude and usually not appreciated.

**"You'll never have to worry about him/her growing up -- you'll always have your baby!"** Children with Down syndrome do grow and mature just like any other child. This comment implies an outdated notion that individuals with Down syndrome do not develop the self-help skills to live more independent lives and continue to be dependent on their parents into adulthood. Parents of a newborn do not want to think ahead to their golden years with an infantile adult still at home.

**"I had a friend who had a baby with [insert congenital disability here] and her husband up and left her."** While it is true in general that parents of children with disabilities have a higher divorce rate, it is NOT true that families of children with Down syndrome have a higher divorce rate than the general population. [American Journal on Mental Retardation, 2008]

**"S/He doesn't LOOK like s/he has Down syndrome. Are you/the doctor sure?"** Doctors do not make this diagnosis lightly and the chromosomal analysis done to confirm the diagnosis is definitive.

**"Does it run in your family?"** There are some infrequent cases where the likelihood of having a child with Down syndrome at any age will run in families. This inquiry is akin to asking whose fault it was that the child has Down syndrome, the mother or father. Only if you are a blood relative and have a health reason for asking (such as considering having a child, considering genetic counseling), should you ask this question and do it in a very sensitive manner after doing your research.

**"S/He'll grow out of it." or "We'll pray that he'll be cured."** It is not likely that Down syndrome will be cured in our lifetime although there are many advancements in scientific research that will help with the effects that the 21st chromosome has on the physical health and mental development.

## **Things TO say**

These are the things parents have found comforting or made them feel good:

**"Congratulations!"** They just had a baby! What better response to show that you love them and their baby than to say congratulations. If the hospital allows it, a bottle of champagne could be greatly appreciated. Some parents, however, have said that this rang hollow if their child was facing serious medical issues like heart surgery.

**"He/She looks just like you" or "Look at that hair!"** Say what you'd say to the parents of *any* new baby. Unless the baby is adopted, s/he probably *does* look like someone in the family. All of the baby's genes are from the family. My son looked exactly like my daughter did when she was just born. Friends and family who actually 'did' something like read about the disability (or find information on the web!) learned about this. This really means something to the new parents. It shows love and concern for the baby and acceptance into the family.

**Offer to babysit.** It is a fear of the new parents that their family will not accept the new baby. By saying something like, "Well, when are you going to let me babysit?" you are showing the new parents that you want to be part of the baby's life. This will be a great relief to them.

**"He/She will do fine."** The new parents are probably pretty worried. They might not know much about Down syndrome and may be concerned about possible medical problems. (Down syndrome might not be their biggest concern if they're facing heart surgery or other immediate complications) Having a positive attitude will rub off on them. They don't need pessimism or negativity from their loved ones.

**"We'll all learn from him/her."** This is another good way to show that you intend on being part of their lives. After all, how can you learn from their new baby if you are ashamed of him/her? Their new child will be an opportunity to learn about love, acceptance, and respect for the disabled.

**"We will always be here to help."** Another very good way to show that you are going to be there. Let the new parents know that you intend on being part of their lives.