

An Open Letter OB/GYN, L&D Nurses, Midwives and Pediatricians: How to Deliver A Diagnosis of Down Syndrome

Dear Medical Professional,

I am the parent of a son with Down syndrome, Eli, who is the love of my life. I did not know that Eli was going to be born with Down syndrome and it was a difficult adjustment to make. Those first interactions with my OB/GYN and Eli's pediatrician made that adjustment even more difficult (I will explain why below). It is clear that I'm not alone in this story. About 90% of families with children with Down syndrome report that they were not told this news (prenatally or postnatally) in a supportive manner. I want to share with you some lessons from those experiences with the hope that you might be able to be a "better messenger" for this usually undesired and unexpected news.

Most often, parents do not know that they are going to have a baby with Down syndrome. In addition to grieving for the baby that those parents have envisioned for nine months and didn't get (the one with 46 chromosomes), they now have to wrap their heads and hearts around what it means to parent a child with Down syndrome. Just the medical issues alone can be daunting – and then you throw the developmental concerns and lifelong issues on top of that. It makes for a stressful combination. The doctor who delivers this news carries a lot of power and the ability to impact how those parents take their first steps and feelings on this new journey.

It was the on-call pediatrician who delivered the news of Eli's diagnosis to us. Eli was in the NICU with my husband and I was recovering from a caesarian section. The pediatrician approached my husband, and flatly said, "I'm 99% certain that your baby has Down syndrome. I'm going to go tell your wife and I'll be back in a 3 hours to answer questions." Here's what was wrong with that scenario: my husband and I weren't together, no one was holding Eli – so he became the "specimen", and she wasn't available to answer any questions at that moment. I am forever grateful that even in that moment, my husband knew that he should deliver the news to me rather than that doctor.

After this diagnosis (which was 3 hours after Eli's birth), I didn't see or hear from my OB/GYN for over 48 hours. When she finally arrived, she apologized for not coming earlier – said that she "just didn't know what to say" and she was "so sorry to hear about Eli's Down syndrome." Really, a medical professional was so devastated over the birth of my son that she didn't know what to say, other than "sorry"? That not only broke my heart, but made me realize that this was going to be a long road of people who didn't accept my son. They were sorry that he was born. I had to muster everything in my core to become his loving, protective mother in that moment. It wasn't easy given some of the messages that I was getting – from professionals.

Being the first point of contact for new parents of a baby with Down syndrome, or any disability, holds a lot of power. I've tried to put together a few tips that can help you utilize that power in such a way that honors the child and gives parents hope, encouragement and support. Here are my hopes:

- **Remember that your words and demeanor will be seared in those parents' minds forever.** Take the time to think this through and do your best. It changes lives and attitudes.
- **Keep a positive and supportive manner.** Parents pick up on your voice and facial expressions. Don't sugar coat things, but don't be apologetic, overly concerned or grief-stricken.
- **Don't say "I'm sorry."** You can congratulate the parents on the birth (or impending birth) of their baby, and then also add and explain that you need feel the need to test the baby for Down syndrome.
- **For expectant parents: don't ask when the family wants to schedule a termination appointment.** Offer resources (discussed below) and allow families to come to their own decisions once they have accurate information. Don't rush families.
- **Use proper and people-first terminology.** It's not "Down's baby," it is "baby with Down syndrome" or "baby with Trisomy 21." It's not "mentally retarded," it is "intellectual disability."
- **Share accurate and up to date information.** There has never been a better time to have a baby with Down syndrome. Medical and educational advances now allow individuals with Down syndrome to live full, healthy and happy lives. They read, have relationships, have jobs and go to colleges. We can give you *New* and/or *Expectant Parent Packets* to give to new families – call us at the Down Syndrome Connection of the Bay Area, (925) 362-8660, and we'll get them to you. Your goal should be to give families hope rather than fear.
- **Don't talk about the baby to other medical professionals in front of the parents.** Too often, parents learn of the news when the OB/GYN and/or nurses are "talking among themselves." Respectfully include the parents in all of your discussions.
- **Don't talk about possible medical complications in that first conversation – unless there is a clear immediate need.** Let some bonding occur and medical tests, etc. will come.
- **Connect them with local resources.** The DSCBA is a wonderful support for new and/or expecting families. We have up to date information, a parent mentor program, support groups and much more. Please let us help.
- **If possible, deliver the news when the parents are together, the baby is present and is being held.** This is the first moment of those parents needing to support one another through this unexpected journey. Being unified physically and with their child allows that first frightening moment to be heard "as a family." They are in it together.

I respect that you do great work – thank you for all that you do for babies and families. I hope that this letter will allow you to continue to do great (and maybe even better) work. Please know that we at the Down Syndrome Connection of the Bay Area are always available to support you, your families or anyone you know whose life might be touched by Down syndrome.

Sincerely,

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