

How to deliver the news? New advice for doctors diagnosing prenatal Down syndrome

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New prenatal tests for Down syndrome are soon to be offered to all pregnant women across the United States, yet telling an expectant couple that their child will be born with Down syndrome is a task very few physicians are trained for, claims research published in the *American Journal of Medical Genetics*. The study, which reviewed decades of surveys and interviews, offers several recommendations for how physicians can best deliver the news.

A 29-member research team, led by Dr. Brian Skotko from Children's Hospital Boston, supported by the National Down Syndrome Society and informed by experts from across the field, reviewed surveys and research ranging from 1960 to present day to consider how prepared physicians felt they are to deliver a diagnosis. They also studied the opinions of couples who had received the diagnosis to determine the best way of delivering the news.

"Down syndrome (DS) remains the most common chromosomal condition. It occurs in one out of every 733 live births," said Skotko. "Nearly every [obstetrician](#) can expect to have a conversation with expectant parents about the realities of life with DS, but very little research has been dedicated to understanding how physicians should communicate the news."

The team found that in a 2004 survey approximately 45% of obstetric fellows rated their training as "barely adequate or nonexistent"; a similar survey four years later found little change as 40% thought their training

was "less than adequate." In 2005 a survey of 2,500 medical students showed that 81% believed they were "not getting any clinical training regarding individuals with [intellectual disabilities](#)."

To improve this scenario the team set out to answer five critical questions which every physician should consider before delivering a diagnosis: Who is the best person to communicate the news? When is the best time to share the news? Where should the news be delivered? What information should be offered? How should the diagnosis be communicated?

The team found that while many sources are available, from trained counsellors to midwives, expectant couples prefer to receive the news from the health care professional with the most knowledge, the physician.

Also, women who decided to undergo definitive prenatal testing for DS prefer to receive the diagnosis as soon as possible in the company of their husbands or partner, while women who had arranged for the diagnosis to be delivered by a phone call were better prepared for the news than those who received the news from an unarranged call. Women who received the diagnosis through an unscheduled call expressed intense resentment towards their obstetricians and counsellors.

Regarding the amount of information a couple should be given, mothers emphasised that they should be provided with up-to-date information about DS, its causes and the expectations for a child living with DS today. This information should include descriptions of common or anticipated health conditions seen in infants and young children.

On top of this, parents found that they benefited from personal stories that demonstrate the potential and possibilities for children with DS and if possible if possible contact information for other parents who have

children with DS should be made available.

Mothers emphasized that at the time of a diagnosis, physicians should discuss all options available to them, including continuing the pregnancy, offering the baby up for adoption after birth, or pursuing termination. In a survey of 71 women from the Netherlands who terminated their pregnancy after a diagnosis of DS, 34% indicated that the option of continuation was not raised.

Finally physicians should be mindful of how they communicate the news. In the largest study most mothers requested that physicians should not begin a conversation by saying "I'm sorry" or "unfortunately I have some bad news," instead they should use neutral and nondirective language.

Unsurprisingly the team also suggests that outdated and offensive language such as "mongolism" should be avoided and instead phrases such as "a fetus with [Down syndrome](#)" should be adopted.

Ultimately the research review found that mothers who received the diagnosis prenatally and continued their pregnancy were happier with the birth of their child than those who received the diagnosis after the baby had been born. Receiving the diagnosis in advance seems to allow parents the needed time to overcome the shock and initial grief of the diagnosis and begin preparing and celebrating the upcoming birth of a child.

"Of the studies reviewed nearly all mothers reported feelings of initial shock, anger and fear following the diagnosis," concluded Skotko. "Yet, these same mothers indicated that if physicians were to implement a few simple measures, as research suggests, the experience could be more sensitive to their emotions and needs."

Source: Wiley ([news](#) : [web](#))

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