
DELIVERING A PRENATAL DIAGNOSIS

Communicating a prenatal or postnatal diagnosis or screening test results to a family can be overwhelming for both the clinician and the patient. That moment is often described as a flashbulb memory that a patient remembers in detail for a lifetime. Fortunately, best practice recommendations outline suggestions for discussing a prenatal or postnatal diagnosis so that clinicians can frame that moment in sensitivity and compassion (Skotko et al., 2009; Sheets et al., 2011). It's also important to remember that patients consider the moment they receive screening test results and also the moment when they receive diagnostic results as part of their diagnosis journey.

Best practice guidelines for communicating a prenatal diagnosis include the following recommendations (Skotko et al., 2009):

- Clearly outline the differences between prenatal screening and diagnostic tests. Importantly, patients need to understand that screening tests (including cell-free DNA and non-invasive prenatal screening tests) indicate a patient's chances for having a baby with a number of genetic conditions. However, the screening tests are not definitive because false positives do sometimes occur. Only chorionic villus sampling and amniocentesis are considered diagnostic. (Gregg, 2013)
Note: If screening results indicate that the fetus likely has a condition, you need to make sure expectant parents understand that the results are not conclusive, but the majority of parents want condition-specific information right away. If they do not receive that information from their clinician, they will likely perform an online search on their own. Moreover, some parents will still decline diagnostic testing and will not receive any information if your policy is to wait on giving condition-specific information until after diagnostic confirmation.
- If a pregnant woman wants to undergo testing, ask her about why having a diagnosis prior to birth would be important to her. This can help better guide any future conversations about a test result.
- When possible, deliver the results in person or at a pre-established time by phone. Determine a standard way of handling all results and tell patients about that up front so that they don't get the impression that an appointment or phone call is only scheduled if results indicate a diagnosis.
- Personally deliver the diagnosis as soon as possible following definitive prenatal testing. Use commonly understandable terms and convey information in a patient's native language, when translation is available.
- Each condition detected with prenatal testing has different outcomes, and each expectant parent reacts differently based on his or her background and experience, life circumstances, and perceptions about parenting. Assess the emotional reactions of the expectant parents, and validate these feelings. Use active listening and empathetic responses to offer support. (Sheets et al., 2011)
- If a condition does not cause premature death, use neutral language such as, "The results indicate..." and not begin with, "I'm sorry," or "Unfortunately, I have some bad news..."
- Provide accurate and up-to-date information about the genetic condition and contact information for local support organizations.