



DOWN SYNDROME INFORMATION ALLIANCE

Delivering a Diagnosis of Down Syndrome

Delivering the Diagnosis

After 20 years, mothers can still recall with nearly 82% accuracy the first conversation about Down syndrome.

WHO should be present?

- Mother and father present
- Physician - Both obstetrician and neonatologist, if possible
- Nurse
- Social Worker

WHEN should you share the diagnosis?

- Mothers want to know as soon as possible, *even if the diagnosis is not confirmed*
- Parents already know that there is something different about their child

WHERE should the discussion occur?

- Private room
- No other medical personnel; no visitors
- Mother and father/support person
- Provide parents a private place to be alone immediately after disclosure

WHAT information should be shared?

1. Basics

- What is Down syndrome?
- What is its cause?
- What does it mean for the family, in practical terms?

2. Balanced, realistic information

- Resources
- Parent-to-parent mentoring

3. Limit information to the most **immediate** or common medical conditions:

- *Cardiac defects, mild/moderate intellectual disability, hearing problems, ear infections.*

The Importance of The Conversation

What parents remember:

- Physicians and nurses offering congratulations
- The first words that healthcare providers used, which set the tone for the rest of the conversation.



For more information contact DSIA at info@downsyndromeinfo.org or 916-658-1686.

www.downsyndromeinfo.org