



DOCTOR DISCUSSION GUIDE

Managing Down Syndrome

Although a diagnosis of Down syndrome for your baby may come as a shock and feel intimidating, your baby can still live a full and wonderful life. Asking the right questions during your conversation will help you know what to expect and how to better navigate this condition. Familiarize yourself with these common terms before your appointment to help facilitate your discussion.

Vocabulary to Know

Your doctor might mention these common terms. Here's what they mean.

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| Chromosome | A strand of DNA that is encoded with genes. |
| Trisomy 21 | The medical term for the condition that is known as Down syndrome. Trisomy 21 is named because there are three copies of the 21st chromosome in people with this condition instead of two. |
| Hypotonia | A common trait among people with Down syndrome is low muscle tone, also known as hypotonia. This means that the muscles are not as rigid at rest of the muscles of people without hypotonia. |
| Developmental Delay | Most people with Down syndrome develop more slowly than typical children. They are capable of learning and doing most anything that typical kids can do, the process to learn just takes longer. |
| Early Intervention | These programs provide therapies (typically speech, occupational, and physical therapy) for children with developmental delays under the age of 3. |
| Congenital Heart Defect | A problem with the structure of the heart that is present at birth. Fifty percent of babies with Down syndrome have some type of congenital heart defect. |



Questions to Ask

These questions will help you start a conversation with your doctor about how to best manage Down syndrome.

About Symptoms

- How do you know my child has Down syndrome?
- Will my child get sick more often because they have Down syndrome?
- How will Down syndrome affect my child?
- Is there a cure for Down syndrome?
- What are the most common co-existing conditions that occur with Down syndrome? Do you know if my child has any of them?

About Causes & Risk Factors

- How did my child get Down syndrome?
- If this is a genetic condition, does that mean other people in my family have had it?
- Did I do anything to cause my child to have Down syndrome?

About Diagnosis

- What kinds of tests can you do to diagnose Down syndrome?
- How accurate are the diagnostic tests?
- Do I have to have an amniocentesis to diagnose Down syndrome during pregnancy?
- If I my blood test during pregnancy shows a higher risk for Down syndrome, how can you be sure it's accurate?

About Treatment

- Is there anything that can be done to treat or cure Down syndrome?
- Are there medications that can help my child develop like typical children?
- My child with Down syndrome also has a heart condition, what do I need to know about that? Will he need surgery?
