



Myths and Truths

Myth: Down syndrome is a rare genetic disorder. Truth: Down syndrome is the most commonly occurring genetic condition. One in every 691 births in the United States is a child with Down syndrome.

Myth: Having a child with Down syndrome will be a burden on a family. Truth: Children with Down syndrome have many gifts and talents. They bring joy to their families lives and enhance the world. There are many families currently seeking to adopt children with Down syndrome as they feel this will enhance their family.

Myth: All individuals with Down syndrome will have severe developmental or intellectual delays. Truth: Most people with Down syndrome have cognitive delays that are mild to moderate. IQ is not an adequate measure of the functional status of people with Down syndrome. People with Down syndrome have great potential when given the opportunity to succeed.

Myth: Individuals born with Down syndrome do not experience full and meaningful productive lives. Truth: Individuals with Down syndrome live at home with their families, in group homes or homes of their own. They are integrated into the regular education system and are active participants in the vocational, social, religious and recreational activities of the community. Many individuals will go to college, work and lead meaningful lives.

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Prenatal Diagnosis Links

Down Syndrome Pregnancy—

A program administered by the National Center for Prenatal and Postnatal Resources at the University of Kentucky's Human Development Institute provides honest, compassionate, medically-reviewed, and informative support for those continuing a pregnancy post-diagnosis or waiting until birth for a confirmed diagnosis.

www.downsyndromepregnancy.org

Letter Case—

Understanding a Down Syndrome Diagnosis is an accurate, balanced, and up-to-date booklet for use when delivering a diagnosis of Down syndrome.

www.lettercase.org

Down Syndrome Diagnosis Network—

Supports families with current information and real life accounts of life with Down syndrome during the prenatal to early childhood phases. DSDN is committed to facilitating unbiased, family-centered discussion.

www.dsdiagnosisnetwork.org

Brighter Tomorrows—

This website is designed to offer you information about Down syndrome, to allow you to explore frequently asked questions, and to give you a glimpse into the lives of children and young adults with Down syndrome.

www.brightertomorrows.org

Sharing the News



Helping Families Understand Their Babies Down Syndrome Diagnosis



Down Syndrome Connection
OF NORTHWEST ARKANSAS

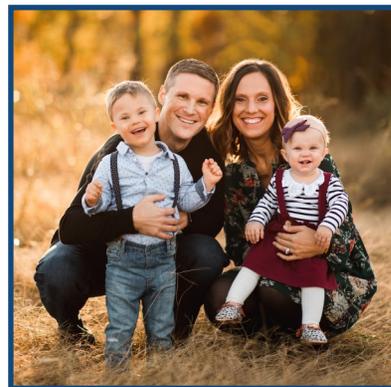
Some Helpful Tips

- Celebrate the birth of the baby with the family and encourage them to think positively about their baby's future.
- Use people first language at all times e.g. "your baby has Down syndrome" NOT: "A Down's baby".
- Give the diagnosis in a private setting as soon as possible.
- The baby should be held by the parents or the physician when discussing the diagnosis.
- Both parents should be present for the initial diagnosis. In the case of a single mother, please be sure that a significant other, the birth coach or a family member is available to offer support.
- There are many different ways to understand, accept and cope with this information. Do not pass judgements or make assumptions about a family's reaction to the news.
- Ask the family what, if any, additional information would be helpful to them.
- Ask the family if you may contact the Down Syndrome Connection of NWA as a step towards helping the family.

The Important Role of the Medical Professional

- As a medical professional you will be the first touch point for a family. Your attitude will have a strong effect on the family—they look to you as the expert.
- Sharing positive and accurate information helps your families accept their child's diagnosis and begin the bonding process with their baby.

Talking openly with the family will help them to deal with the diagnosis. What you don't say, may be as powerful as the things you do say. If you are not sure what to say, let us help you! Please be sure to refer the family to the Down Syndrome Connection of NWA for assistance.



Individuals with Down syndrome have unlimited potential when given opportunity and support.

Your First Words to a Family Will Have a Life Long Impact

Congratulations on the birth of your baby (use baby's name). I have some information about your baby that I need to share with you. It looks as though your baby may have Down syndrome. We'll do some tests and let you know the results as soon as possible. For now I just want you to know your baby seems to be doing great. I have some great resources available for you about Down syndrome. What information would be most helpful for you? Do you have any questions you would like me to answer?

Other parents tell us that meeting another family was probably their most valuable experience. Would you like me to contact the Down Syndrome Connection of NWA to request a parent to parent visit for you? The DSCNWA will provide you with a gift package full of resources on Down syndrome, put you in touch with other families and provide you support throughout your child's life. The social worker here at the hospital may also be able to help you access resources.

You should contact your local early intervention program as soon as possible.

They will help you set up a series of therapies to get your baby off to a great start! The therapist will work with you to help you learn more about your baby's developmental needs.

You may be feeling a whole range of emotions right now. Whatever you are feeling is normal.

Many families tell us they were shocked, grieved, and were angry when first learning of their child's diagnosis. Be sure to talk about your feelings and express them openly. This will help you to overcome any concerns you have and bond with your baby. No one can predict what your child's future will hold.

