
Dear Parents,

We want to congratulate you on the birth of your baby! When our son was born we had lots of friends who were supportive of us but they didn't know any more about Down syndrome than we did. I wanted quality information and the opportunity to share joys and challenges with other parents facing the same new life that we were. The Down Syndrome Association for Families (of Nebraska) started in 1995 to provide hopeful, realistic information and allow families to learn from each other.

The Down Syndrome Association for Families (*DSAF) is now a non-profit, 501(c)3 organization. We host different age-level meetings: Little Stars for families with children birth through preschool, Super Stars for school age level kids, DSAF Teens for teens through age 21. The kids who started with our group are now in their mid teens to nearly 20 so we will be establishing a group for post 21 young adults. We also have all group meetings throughout the year: our Pizza and Ball Night, World Down Syndrome Day Celebrations, Annual Picnic and Swim Party, Roca Berry Farm Pumpkin Patch Day and our Annual Christmas Brunch (both Santa and the Grinch have visited!). We have had opportunities for parent coffees, informative presentations from using technology to education conferences for parents, teachers and therapists. We've supported a Bike Camp to help our kids learn to ride a bike, had sibling workshops and sibling get-togethers. Our goal has always been to reach and support all families who have children with Down syndrome in the state of Nebraska. We have a program called S.E.A.S. (Summer Enrichment Activities Support) to assist kids taking part in typical summer classes and programs. Our website, www.dsafnebraska.org continues to provide more information for families. Our newsletter comes out about six times per year and is available mailed to homes and on our website. We have a lending library available to parents and we also provide books to schools and libraries.

Our main fundraiser is our Capital City Step UP for Down Syndrome Walk (SUDS Walk) which occurs the first Saturday of October at Antelope Park in Lincoln. The walk started in 2002. This is a wonderful family friendly time. People setup teams like Paul's Posse, Izabella's Voice, Ethan's Entourage, Bubba's Bouncers and many other fun names. We have prizes for the team who raises the most money and the team with the most walkers. There's a raffle and a special raffle for the individual with Down syndrome. The SUDS Walk provides a great opportunity for community awareness of who our kids are and the many things they are capable of accomplishing when given opportunities. Information and pictures about the SUDS Walk are on our website.

You can contact us at info@dsafnebraska.com or call 402-421-1388. Our Medical Outreach Team has a First Response Team of parents trained to visit new families at the hospital or contact new families a few weeks after their baby is born. It can be very hard for new parents to have to make the first call for information. We are respectful of your desires for contact and will only contact at your request. We also can pair you up with another family that either has gone through certain special needs like heart surgery or with another family who has a similar mix of children the same age and stage as yours.

With best wishes,

Deb Safarik, Founder/President

A BABY IS A BABY FIRST

There is nothing quite like a baby...there's a lurch in the heart when we touch the beginning of a life in the small person of an infant. For some parents, the lurch is made more poignant, even painful, by the fact of their baby's diagnosis of Down syndrome.

Recently, I've had the great pleasure of holding a number of soft, beautiful babies who have Down syndrome. Their parents want to find out what it all means, what they can do, what to think about the future. The first professional to talk to the parents of babies with Down syndrome tend to discuss the differences parents may see, difficulties babies will encounter. Armed with information about what milestones their child may not reach, what problems she may have, what services they should obtain to avoid potential problems, new parents want to help their babies as soon as possible. So they come to me (and to numerous others) to get this help...to find therapy, activities, and solutions to problems that may or may not exist.

We just don't know, at an early age, in exactly which ways Down syndrome may affect a child. She may be really good at cognitive activities, but have significant delays in movement...thereby falling behind her peers in playground and paper-and-pencil activities. He may be fairly good at gross motor, excelling in sports. Ocular control may be an area of need, or may be perfect. Language may be good, or may need lots of work. However, one thing we know for certain..babies don't deal with these things no matter what their chromosomes look like. They lie down and expect to be carried, cuddled, talked to, fed and generally catered to. They learn they are lovable, cute, and the center of the universe. They begin to know who their family members are, and who is the soft touch in the house in the middle of the night.

If these adorable creatures have Down syndrome they are at risk for certain physical and cognitive delays. It behooves parents to keep an eye open for problems that could arise. It's important that they know something about their child's diagnosis so that they can be alert and helpful. But my belief is that the most important things that parents of babies with Down syndrome can do are exactly those things that all parents do. You know: they cuddle, feed, sing and love. Not the kind of things you need a Developmental Therapist for... or any other therapist, for that matter.

I want to be clear. Young children with Down syndrome often show delays that need to be remedied so that these kids can be happy with themselves and do their very best. Very young babies with Down syndrome have specific concerns about early development. And doubtless, parents will find themselves driving this child about for ear infections, speech therapy, developmental evaluations, etc. But the main advice I have for parents of new babies with Down syndrome boils down to this: **You have a beautiful new baby.**

There will be some areas that need work, but what you have right now ..

IS PRECIOUS AND PERFECTLY RIGHT.

Kate Sefton, Master Developmental Therapist

Reprinted with permission from the National Down Syndrome Congress web-site.



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Each year
Nebraska
welcomes
approximately
37 babies born
with Down
syndrome.



Publication of this book sponsored by

JEO Benefit Golf Tournament





Brand New Day



The "Truths" About Down Syndrome

Down syndrome, discovered by John Langdon Down in 1866, is a frequently occurring chromosomal abnormality affecting one out of every 691 children born, resulting in a wide range of developmental delays. It is caused by a cell division error of unknown origin. Over 400,000 people in the U.S. alone are affected by Down syndrome. Parents of all ages give birth to babies with Down syndrome.

A child born with Down syndrome is just that - a "child" first, with a diagnosis of Down syndrome - not "a Down syndrome child" or "the child is Down syndrome". Thanks to early intervention services, high quality education programs, a stimulating home environment and medical technology, children with Down syndrome stay closer to their age-appropriate level than ever thought possible. They run, jump, read, sing, smile, cry, and have scraped knees just like everybody else. Children with Down syndrome are not segregated, but attend school with their typically developing friends, and many even attend college, live independently and join the workforce.



**There are more than
400,000
people living with
Down syndrome in
the United States.**

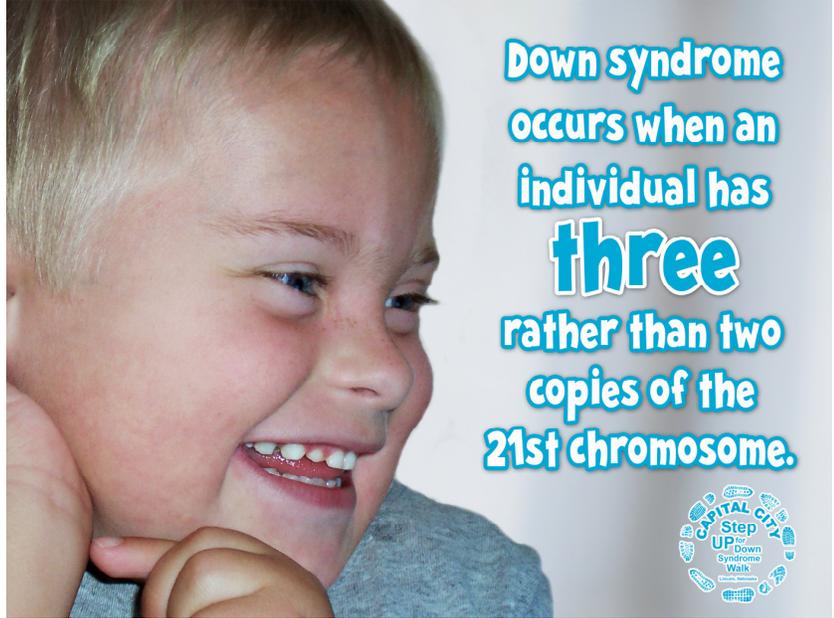
CAPITAL CITY
Step
UP for
Down
Syndrome
Walk
Lincoln, Nebraska

 Images for a lifetime
photography

What is Down syndrome? (A summary)

Down syndrome affects people of all ages, races and economic levels. It is one of the most frequently occurring chromosomal abnormalities found in humans, occurring once in approximately 691 live births. Over 400,000 people in the United States alone, are affected with Down syndrome.

All people with Down syndrome have an extra, critical portion of the number 21 chromosome present in all, or some, of their cells. This additional genetic material alters the course of development and causes the characteristics associated with the syndrome.

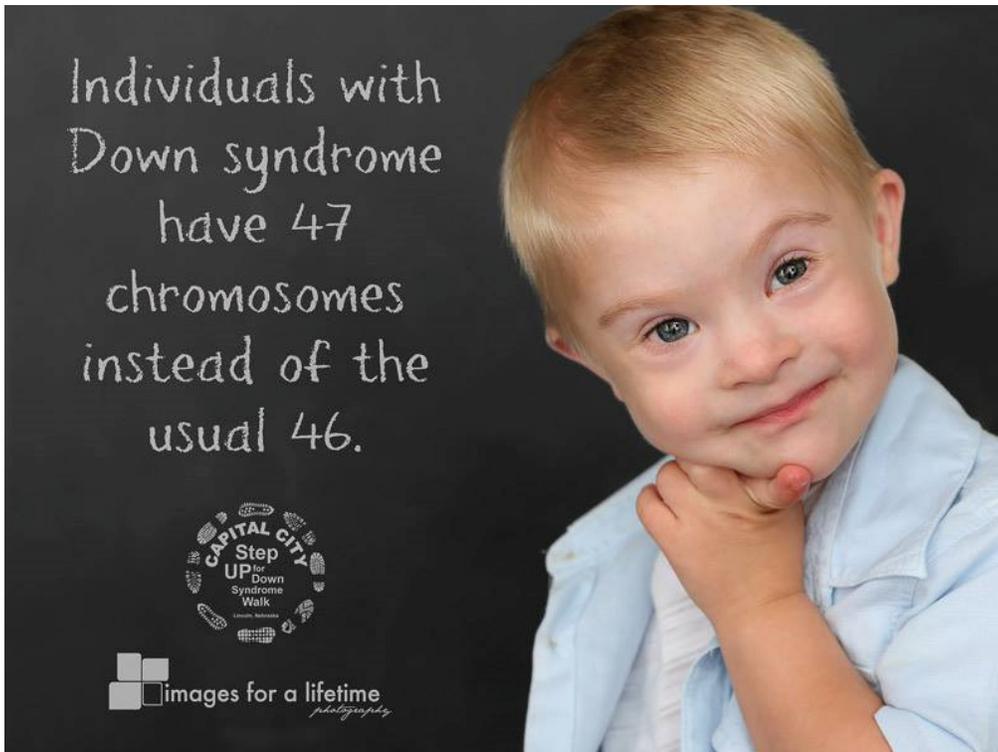


From the Down Syndrome Guild of Greater Kansas City, *New Parents Guide*

What is Down syndrome? (A closer look)

Down syndrome is a chromosomal disorder characterized by the presence of an extra #21 chromosome. Instead of having 46 chromosomes in each of his/her cells, a person with Down syndrome has 47. The extra chromosome may be derived from either the egg or the sperm. It is believed that during cell division of a sperm or egg, the two #21 chromosomes do not separate properly (nondisjunction). Thus, one cell will have an extra #21 chromosome which later, if united with a normal germ cell which has among others one

#21 chromosome, may lead to trisomy 21. The first cell at conception then has 47 chromosomes instead of "normal set" of 46 chromosomes. When this cell with three #21 chromosomes continues to multiply, and the pregnancy is carried to term, a baby with Down syndrome will be born. This form of chromosome error, trisomy 21, is found in about 95% of persons with Down syndrome.



The 5 percent of babies with Down syndrome who do not have trisomy 21 may have Translocation, Mosaicism or partial trisomy. In translocation Down syndrome, there are also three copies of the #21 chromosome. However, one of the #21 chromosomes is attached or translocated on another chromosome, usually a #14, #21, or #22 chromosome. Three to four percent of children with Down syndrome have translocation. About one third to one half of translocations are inherited from one of the parents. When this happens, the carrier parent has the normal amount of genetic material, however one of the #21 chromosomes is attached to another chromosome. As a result this individual's total chromosome count is 45 instead of 46. The carrier parent is clinically unaffected because there is no loss or excess of genetic material. Doctors refer to a parent like this as a balanced carrier.

Another form of Down syndrome is known as mosaicism, which affects about 1 percent of all people with Down syndrome. In mosaicism, a faulty cell division most often occurs in one of the earliest cell divisions after conception. This is in contrast to other types of Down syndrome when the error in cell division occurs before fertilization. As in trisomy 21, something causes one of the cells to divide incorrectly. But when this occurs in one of the early cell divisions, only some of the cells of the growing embryo have the extra #21 chromosome and the other cells have the normal number of chromosomes. Depending on the ratio of normal cells to trisomic cells, the child may have fewer Down syndrome features as well as higher cognitive abilities.

Although details of the mechanism of nondisjunction are for the most part unknown, the presence of three copies of the #21 chromosome causes a genetic imbalance that alters the typical course of growth and development of the fetus and child with Down syndrome.

What causes Down syndrome?

Down syndrome occurs in approximately one out of every 691 live births; it is one of the most often observed chromosome anomalies. Scientists have investigated the causes of Down syndrome for the past century. So far its exact cause has eluded discovery. Although many factors have been considered to be possible causes, the age of the mother is the most often discussed factor related to the likelihood of having a baby with Down syndrome. It has been known for some time that the risk of having a child with Down syndrome increases with the advancing age of the mother, i.e., the older the mother, the greater chance that she may give birth to a child with Down syndrome. The risk at age 20 for instance is about 1 in 1600, the risk at age 35 is 1 in 365 and the risk at 40 is 1 in 100. However, because there are more younger women having babies, 75-80% of all children with Down syndrome are born to women under 35 years of age.

If I already have a child with Down syndrome, is the risk higher that I will have another child with Down syndrome? If your baby has trisomy 21 the risk for having another child with Down syndrome is approximately 1 in 100 or 1% in addition to the mother's age related risk. For families who have a baby with translocation Down syndrome, the risk of recurrence is also about one in one hundred unless the condition is inherited from one of the parents. The risk of recurrence depends on the type of translocation and the sex of the carrier parent.



What are the physical characteristics of Down syndrome?

The following characteristics are most commonly associated with Down syndrome, but can also be found in the general population. There is some variety of physical features among babies with Down syndrome; not every baby possesses all of the characteristics. Moreover, there is no correlation between the number of characteristic features a baby has and the child's cognitive ability. Babies with Down syndrome usually have low muscle tone, called hypotonia. This means that their muscles appear relaxed and feel "floppy".

The baby's face may be broader and his/her nasal bridge may be flatter than usual. Often children with Down syndrome have a small nose. The child's eyelids may appear to slant upward and may also have small folds at the inner corners (epicanthal folds). The baby's mouth may be small and the roof of the mouth may be narrow. The baby's ears are often small and the upper part of the ear may fold over. Babies with Down syndrome usually have small heads. The difference in size, however, is not usually noticeable. The back of the head may be flatter and the neck may appear shorter. In newborns, there may be loose folds of skin on the back of the neck, but these tend to disappear later with advancing age.

The child's hands may be smaller, and his/her fingers may be shorter than other children's. In about 50% of children with Down syndrome only one palmar crease is observed, and the 5th finger may be curved slightly inward. Usually, the feet of babies with Down syndrome appear fairly normal, but there may be a wide gap between the first and second toe.

Because children with Down syndrome have an extra #21 chromosome, they may have features that resemble other babies with Down syndrome in some way. However, they will also resemble their parents, brothers and sisters.



What are the developmental aspects?

The baby with Down syndrome will grow and develop like other babies. He/she will do all the things a typical child does, only somewhat later. Compared with typical children, individuals with Down syndrome are usually smaller and their development is somewhat slower. For example, instead of walking at 12 to 14 months, a child with Down syndrome may learn to walk between 18 and 36 months. Most children with Down syndrome will display a delay in their speech and language development. It should be noted that there is a wide variation in the mental, behavioral and developmental progress in children with Down syndrome. A caring and enriching home environment, early intervention and improved special education services have a positive influence on the child's development.





What about adults with Down syndrome? Where do they live?

Today, adults with Down syndrome have choices about where they live and with whom they live. Some live in apartments, condominiums, or houses with roommates and/or with support services and some adults choose to remain in homes with their parents or siblings.

Do adults with Down syndrome work?

Adults with Down syndrome are working at a variety of jobs ranging from regular competitive jobs in the community, to supported employment or sheltered employment. People with Down syndrome are clerical workers, computer operators, assistant coaches, photographers, teacher assistants, etc. People with Down syndrome are becoming more and more contributing and tax paying members of their communities.

What is the life expectancy of people with Down syndrome?

Improved medical care has primarily prolonged the life span of people with Down syndrome. It is not unusual for people with Down syndrome to live into their 50's, 60's and even 70's.

References: Pueschel, Siegfried M., M.D., Ph.D., J.D., M.P.H. A Parent's Guide to Down Syndrome: Toward A Brighter Future, 2001.

Reprinted with permission from the National Down Syndrome Congress web-site.

Myths and Truths about Down Syndrome

Myth: Down syndrome is a rare genetic disorder.

Truth: Down syndrome is the most commonly occurring genetic condition. One in every 691 babies in the United States is born with Down syndrome, approximately 6,000 births per year. Today, Down syndrome affects more than 400,000 people in the United States.

Myth: People with Down syndrome have a short life span.

Truth: Life expectancy for individuals with Down syndrome has increased dramatically in recent years, with the average life expectancy approaching that of peers without Down syndrome.

Myth: Most children with Down syndrome are born to older parents.

Truth: Most children with Down syndrome are born to women younger than 35 years old simply because younger women have more children. However, the incidence of births of children with Down syndrome increases with the age of the mother.

Myth: People with Down syndrome have severe cognitive delays.

Truth: Most people with Down syndrome have cognitive delays that are mild to moderate. Children with Down syndrome fully participate in public and private educational programs. Educators and researchers are still discovering the full educational potential of people with Down syndrome.

Myth: Most people with Down syndrome are institutionalized.

Truth: Today people with Down syndrome live at home with their families and are active participants in the educational, vocational, social and recreational activities of the community. They are integrated into the regular education system, and take part in sports, camping, music, art programs and all the other activities of their communities. People with Down syndrome are valued members of their families and their communities, contributing to society in a variety of ways.

Myth: Parents will not find community support in bringing up their child with Down syndrome.

Truth: In almost every community of the United States there are parent support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome.

Myth: Children with Down syndrome must be placed in segregated special education programs.

Truth: Children with Down syndrome have been included in regular academic classrooms in schools across the country.

In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The current trend in education is for full inclusion in the social and educational life of the community. Increasingly, individuals with Down syndrome graduate from high school with regular diplomas, participate in post-secondary academic and college experiences and, in some cases, receive a college degrees.



Myth: Adults with Down syndrome are unemployable.

Truth: Businesses are seeking young adults with Down syndrome for a variety of positions. They are being employed in small and medium sized offices: by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industry, in clerical positions, childcare, the sports field and in the computer industry to name a few.

Myth: People with Down syndrome are always happy.

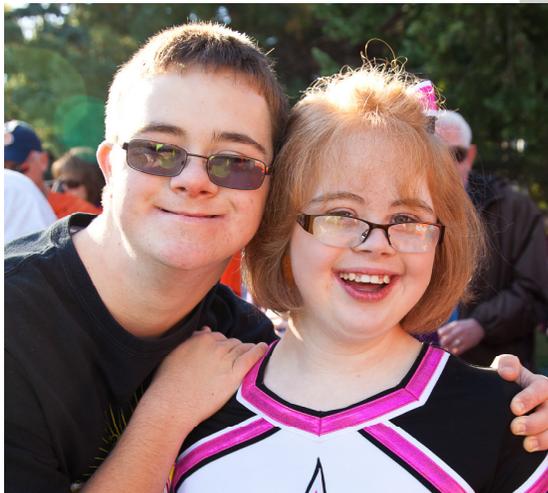
Truth: People with Down syndrome have feelings just like everyone else in the population. They experience the full range of emotions. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.

Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.

Truth: People with Down syndrome have meaningful friendships, date, socialize, form ongoing relationships and marry.

Myth: Down syndrome can never be cured.

Truth: Research on Down syndrome is making great strides in identifying the genes on chromosome 21 that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.



Health issues to address at the hospital or soon after birth

Children with Down syndrome are often at increased risk for certain health problems. Congenital heart defects, increased susceptibility to infection, respiratory problems and obstructed digestive tracts occur with greater frequency among children who have Down syndrome. However, advances in medicine have rendered most of these health problems treatable.

Soon after birth, it is important that you have taken an active role in ensuring the best health care for your child. Some steps commonly recommended include:

- Choose a pediatrician who has experience with children who have Down syndrome or who is eager to learn. The Down Syndrome Association for Families does not endorse any health care provider. However, by contacting other parents, you may ask questions about how they made pediatric care choices for their child.
- Have an echocardiogram. It is important that all children born with Down syndrome, even those who have no symptoms of heart disease, have an echocardiogram in the first 2 or 3 months of life. Symptoms of major heart defects may present themselves as heart failure, difficult breathing and failure to thrive in the newborn period. However, the defects may not be apparent at first. Most hospitals have the capability to perform an echocardiogram and it is often more convenient to take care of this prior to leaving the hospital.
- Ensure that the diagnosis is confirmed via chromosomal karyotyping.
- Have the pediatrician check for gastrointestinal blockage. Some signs of gastrointestinal blockage include vomiting or absence of stools.
- If your child has any feeding difficulties, ask for a consult with a feeding specialist. Most children with Down syndrome have success with breastfeeding.
- Have a hearing test before leaving the hospital. Some children with Down syndrome have hearing loss. With new testing procedures this can be easily detected in newborns.

These points are not meant to be exhaustive and are not meant to replace receiving care and advice from a qualified physician. The above information has been adapted from the Kansas City Down Syndrome Guild New Parent Packet. For more detailed guidelines, a reprint of the Healthcare Guidelines for Individuals with Down Syndrome (published in **Down Syndrome Quarterly**) is provided in Section 3 of this packet.



Breast-Feeding When Your Baby has Hypotonia, Congenital Heart Disease or Down Syndrome

Source: La Leche League International

Babies with special needs are often bombarded with a variety of health problems early on. Those babies who have Down syndrome often face respiratory tract infections and bowel problems. They can benefit from the gentle protection human milk provides. Breast-feeding also helps establish a bond in the midst of the strong emotions and high stress surrounding the birth of a child who has special needs.

Nursing Techniques

Hypotonia (low muscle tone) is common among babies born with Down syndrome, as well as other babies who are born with special needs. Hypotonia may make breast-feeding difficult, but with practice these babies gradually improve mouth and tongue coordination as well muscle tone. This improves speech and language development later in life.

The child who has Down syndrome and/or hypotonia may have instability in the neck joints. Therefore, the baby should be well-supported and nursed in an upright position supported by lots of pillows. This will also help with gulping and choking. The baby may also need to be burped every five minutes or so during a feeding.

Weight gain/heart defects

Babies with Down syndrome are often born with physical abnormalities, such as congenital heart disease, and require extra energy just to maintain adequate circulation. These babies must be closely watched for adequate weight gain. Keeping track of wet diapers is an easy way to monitor weight gain. A healthy baby should have six to eight wet cloth diapers or five to six wet disposable diapers a day. Frequent bowel movements, two to five a day, for the first six weeks, indicate that the baby is getting enough to eat.

According to Combs and Marion, (Pediatric Nursing Mar-Apr 1993) children with congenital heart disease who received any amount of mother's milk, even if it was supplemented with formula, had shorter hospital stays and gained weight more easily than babies who were exclusively formula-fed. The other plus is that breast-feeding is compatible with all heart medications. Once the baby's condition is stabilized with medication, he or she will be more enthusiastic about nursing and will generally not require supplementation.

However, if the baby is not showing signs of adequate weight gain, it may be necessary to give supplemental feedings. Supplements are often necessary for babies who have heart disease due to the excess of energy they use. The mother can pump her own milk for these supplements so that the baby continues to receive the benefits of mother's milk.

If weight gain continues to be low despite frequent nursing and supplementing, make sure the baby is fully awake and actively sucking during nursing. A baby who is very sleepy must be stimulated to receive all the milk he or she needs. Short, frequent feedings throughout the day and tactile stimulation, such as hugs and playing a game like patty-cake, may help.

The benefits last a lifetime

The bond established during breast-feeding reassures the new mother that she is able to help her child mature into a strong and capable individual.

"Breast feeding had made it easier to parent a child with Down syndrome," says one mother. "Not only has it helped Aaron physically and emotionally, it has made life more pleasant for me. I love to hold and nurse him, and he thrives on this bonding contact. We have not had the stress of illness, since human milk has kept Aaron so healthy. His oral development is very good since breast feeding is the best exercise there is!"



I am
amazing
and
impossible
not to love.



This is a FAQ from the La Leche League Web-Site <http://lalecheleague.org/>

Note: Please know that we [the LeLeche League writers] are aware that babies come in two equally wonderful genders. For clarity, we are referring to your baby as "he" because mother is most certainly "she."

Is it possible to breastfeed my baby who was born with Down Syndrome?

How wonderful that you want to give your baby the precious gift of your breastmilk! Babies with Down Syndrome experience special benefits from breastfeeding beyond the myriad of advantages to healthy newborns:

- Breastmilk provides extra protection against infections and bowel problems which babies with Down Syndrome are more likely to develop.
- Breastfeeding improves mouth and tongue coordination, giving a child with Down Syndrome a real developmental advantage.
- The act of breastfeeding provides additional stimulation for your baby.
- Breastfeeding promotes closeness between mother and baby, and enhances mothering skills.

Extra patience and reasonable expectations are critical when breastfeeding a baby with Down Syndrome. Low muscle tone and a weak suck can impede the baby's ability to breastfeed. Here are a few tips that may help you breastfeed your baby:

- Because babies with Down syndrome are often sleepy and placid, you may need to interest your baby through frequent breastfeedings throughout the day, wake him fully before breastfeeding, or provide extra touch and stimulation to keep him alert.
- Pay extra attention to positioning your baby at your breast. Try to keep your baby's body elevated near your breasts with his ear, shoulder and hip in a straight line and use extra pillows for support. See LLLI's FAQ "How Do I Position My Baby to Breastfeed?" for more information.
- If gulping and choking are a problem, try positioning your baby so that his neck and throat are slightly higher than your nipple.
- If poor muscle tone makes it difficult for your baby to latch on well, try supporting your baby's chin and jaw while nursing, using the "Dancer Hand Position." To do this, cup your breast with your thumb above your areola, your index finger pointing outward, and the other three fingers below the areola. Use your index finger to support the baby's jaw while nursing. As breastfeeding enhances your baby's muscle tone, he will be able to support himself.

***Our FAQs present information from La Leche League International on topics of interest to parents of breastfed children. Not all of the information may be pertinent to your family's lifestyle. This information is general in nature and not intended to be advice, medical or otherwise. If you have a serious breastfeeding problem or concern, you are strongly encouraged to talk directly to a La Leche League Leader. Please consult health care professionals on any medical issue, as La Leche League Leaders are not medical practitioners.*

Resources for Additional Information on Breastfeeding:

These publications are available from your La Leche League Leader or from the La Leche League catalogue.

- Breastfeeding the Baby with Down Syndrome by Shelly Wright Timko, BA, Yvonne D. Culp, RN, Julia G. Pindell, BFA, and Roseanne Harakal, BS This unit describes the genetic causes and the conflicts mothers may experience in their decision to breastfeed the baby with Down Syndrome. (No 382-19, 12 pages, \$3.00)
- Breastfeeding a Baby with Down Syndrome Newly revised pamphlet providing education and support for breastfeeding a baby with Down Syndrome. (No 528-24, \$1.95)

LaLeche League

1400 North Meacham Rd.

Schaumburg, IL 60173-4840

Web-site: <http://www.lalecheleague.org>

Local organizations include:

MilkWorks

5930 South 58th Street

Lincoln, NE 68516

(402) 423-6402

Web-site:

<http://www.milkworks.org>

St. Elizabeth

Breastfeeding Center

555 S. 70th Street

Lincoln, NE 68510

(402) 219-7471

Women, Infants and Children

(WIC)

Breastfeeding Promotion and Support in WIC

<http://www.fns.usda.gov/wic/breastfeeding-promotion-and-support-wic>

Nebraska Department of Health and Human Services

<http://dhhs.ne.gov>



You are not alone: For Parents When They Learn That Their Child Has A Disability

By: Patty McGill Smith

Source: Conference Compendium 1998

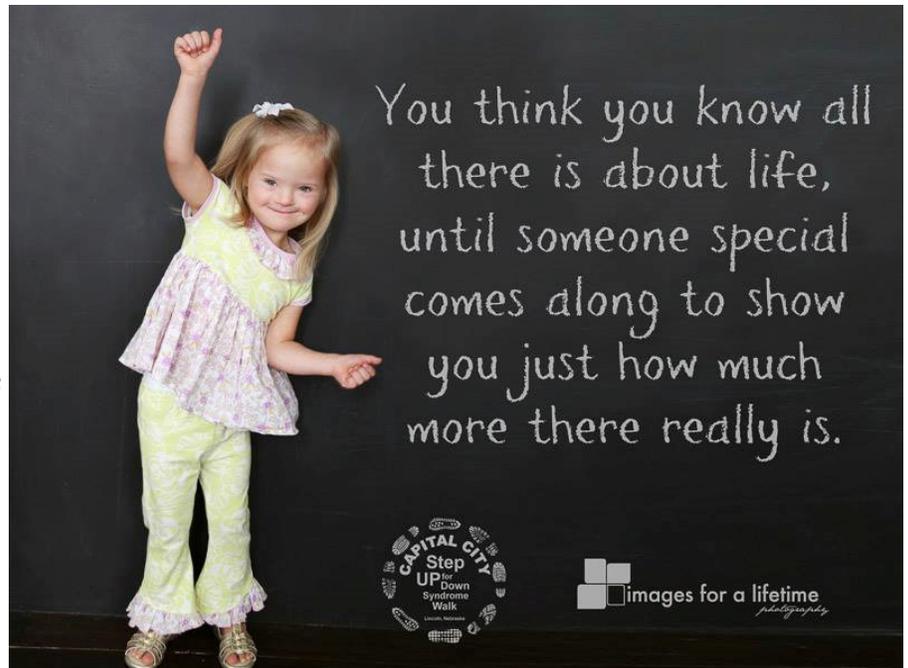
If you have recently learned that your child is developmentally delayed or has a disability, which either is or is not completely defined, this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated - and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help a parent through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge. One of the first reactions is that of denial - "This cannot be happening to me, to my child, to our family." Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of grief and inexplicable loss that one does not know how to explain, nor how to deal with.



Fear is the most immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. In either case, however, fear of the future is common emotion: "What is going to happen with this child when he is five years old, when he is 12, when he is 21? What is going to happen to this child when I am gone?" Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have capability of loving and living and laughing and doing all the things that we had planned?"

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst that it possibly could be. Over the years, I have spoken with so many parents who said their first thoughts were totally bleak. One expects the worst. Memories return of persons with disabilities one has known. Sometimes there is guilt over some slight committed years before toward a person with a disability. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers or sisters in this family and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is guilt - guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?" For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the disability.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?" or "Why my child?" many parents are also saying, "Why has God done this to me?" How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?" One young mother said, "I feel so guilty because all of my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot



understand. You want to find out what it is all about, yet it seems that you cannot make sense of all of the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's disability.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child - a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they will know that they are not alone. There are many constructive actions that you can take immediately, and there are many sources of help, communication and reassurance.

Seeking the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a disability is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress and there would be help of many kinds from many sources. And he was the father of a boy with mental retardation.

My first recommendation is to try and find another parent of a child with a disability, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent-Helping-Parent Programs. The National Information Center for Children and Youth with Disabilities (NICHCY) has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to NICHCY to get local information.

Talk with Your Mate

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life - your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help carry the emotional burden.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of children with disabilities whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Bitterness and Anger

Ultimately, bitterness and anger will hurt you a great deal more than they will affect those toward whom the anger is directed. It is very valuable to be able to recognize your anger and then let go of it. It is understandable that parents will be bitter and angry and disappointed to learn that their child has a serious problem. When you realize that these negative responses tend to hurt you and make you less effective with your child, you can decide to do something about them. Life is better when you are feeling positive. You will be better equipped to meet new challenges when bitter feelings are no longer draining your energies and initiative.



Adopt a Grateful Attitude

It is hard to remain angry when one is grateful. Sometimes, when everything seems to be going wrong, it is difficult to find a cause for gratitude. However, in the scheme of things, if you look around and count your blessings, perhaps positive feelings can overtake the more negative ones.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring. For example, when my child was found to have a disability, one of the other things pointed out to me was that she was (and still is) a very healthy child. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have ever raised.

Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then set about doing that.

Remember that Time is on Your Side

Time heals many wounds. This does not mean living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of the country, assistance is available to help you with whatever problems you are having. While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family, too.



Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest or rabbi. Another may be a good friend or a counselor. Go to those who have been a strength before in your life. Find new sources that you need now.

A very fine counselor once gave me the recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Good things continue to happen each day. Take time to "smell the roses."

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request accurate information. You should not be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember to always ask for copies of evaluations, diagnostic reports and progress reports.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: Get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child is actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

Avoid Judgments

During this period, parents may become judgmental about the way people are reacting toward them or toward their child. Many people's reactions to serious problems are based on a lack of understanding, fear of knowing what to say or fear of the unknown. Therefore, others may sometimes react inappropriately, but you need not use too much energy in being concerned over those who are not able to respond in ways that you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then you do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important or in less need of your love and parenting. Love and enjoy your child. The child comes first; the disability comes second. If you can relax and take the positive steps outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.



Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. In this paper, there are many recommendations to help diminish those feelings of separateness and isolation. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child and that you are not alone.

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Clinical Info: Early Intervention and Down Syndrome

By: Valentine Dmitriev, Ph.D.

Among the many developmental stages through which growing children will pass, the most rapid and developmentally significant changes occur during the first three years of life. It is during this transitional period between infancy and early childhood that children achieve their basic physical, cognitive, language, social and self-help skills. Furthermore, it is expected that these skills will be attained according to predictable developmental patterns, thus laying the foundation for future progress. As a rule, these developmental goals are reached in an orderly manner, seemingly spontaneously, with more successes than failure.

Children with Down syndrome, however, may face some potential difficulties in certain areas of development. Children with Down syndrome do progress through the same developmental stages, but they do so on their own timetables.

What is Early Intervention?

Based upon patterns of development, early intervention is a systematic program of physical therapy, exercise and activity designed to remedy developmental delays that may be experienced by children with Down syndrome. In many instances, the program is individualized to meet the specific needs of each child, and to help all infants and children reach growth milestones in every area of development. Early intervention helps in each of the four main areas of development: gross motor and fine motor skills, language, social development and self-help skills.



When should early intervention start?

Early Intervention should begin any time shortly after birth, and continue until the child reaches age three. The sooner early intervention begins, the better, however, it's never too late to start. Once it is determined that your baby has Down Syndrome, you may contact your local early intervention specialist and arrange for an evaluation and assessment.

What do the terms "milestones" and "key ages" mean?

Milestones refer to a series of skills in the four areas of development which a child is expected to achieve at a designated time, also referred to as a key age which may be calculated in terms of weeks, months or years. It must be remembered that development is a continuous process that begins at

conception and which proceeds stage by stage in an orderly sequence. Each milestone represents a skill which is prerequisite to the next stage in development. In monitoring the development of a child with Down syndrome, it is more useful to look at the sequence of milestones achieved, rather than the age at which the milestone is reached.

How can early intervention benefit a child with Down syndrome?

Early intervention can help in many ways. During the first three to four months of life, for example, an infant is expected to gain head control and the ability to pull to a sitting position (with help) with no head lags and enough strength in the upper torso to maintain an erect posture. Appropriate physical therapy may assist a baby with Down syndrome, who may have low muscle tone, in achieving this milestone. One of the fine motor skills that an infant is expected to achieve is the ability to hold and reach for objects. Here again, the baby with Down syndrome may need help before mastering these tasks. Physical therapy and practice in achieving these and subsequent milestones can assist a baby with Down syndrome in the four areas of development. Early intervention can also prevent a child with Down syndrome from reaching a plateau at some point in development. Thus, the goal of early intervention programs is to enhance and accelerate development by building on a child's strengths and by strengthening those areas that are weaker, in all areas of development.

Why is gross motor development so important?

All areas of development are equally important, although the emphasis changes as the child grows. Nevertheless, before birth and in the first months of life, physical development remains the underlying foundation for all future progress. Babies learn through interaction with their environment. In order to do so, an infant must have the ability to move freely and purposefully. The ability to explore one's surroundings, the ability to reach and grasp toys, to turn one's head in order to follow a moving object with one's eyes, the ability to roll over, to crawl in pursuit of a desired objective, all of these behaviors are dependent upon as well as fine motor development. These physical, interactive activities foster understanding and mastery of the environment, stimulating cognitive, language and social development.

Why does health affect development?

Health plays a major role in everyone's well-being and progress, and this holds true for children with Down syndrome. For this reason, early intervention should begin with a thorough assessment of an infant's health. All health concerns should receive prompt attention to prevent them from interfering with a child's development. Generally, doctors have become much more sensitive to the health needs of children with Down syndrome than they were in the past. Early diagnosis and proper treatment promise better health, and as a result, better developmental progress.

What can I expect in terms of my child's potential and future development?

Early intervention, research and case histories have shown that children with Down syndrome have a far greater potential for learning and for functioning as contributing members of society than it was believed to be possible even 10 to 15 years ago. At the same time, we must remember that each child, whether he has Down syndrome or not, is a unique individual with his own strengths and weaknesses, his own abilities, as well as his own rate of development. Even when milestones are reached on schedule, expectations must be balanced. Low expectations will set limits on what a child can achieve. At the same time, unrealistically high expectations place undue burdens on a child, which may lead to failure. Acceptance of your child is the best approach. Optimistic, yet realistic, expectations plus the ability to recognize and reinforce the smallest increments of progress are the attitudes that are most likely to have a positive effect on development. In this way, early interventions succeed in maximizing achievement.

How can parents benefit from early intervention programs?

Programs of early intervention have a great deal to offer to parents in terms of support, encouragement and information. The programs teach parents how to interact with their infant and toddler, how to meet their child's specific needs and how to enhance development. Furthermore, early intervention centers give parents the opportunity to share their concerns with other parents.

How can I find an early intervention program?

Today, every state in the US has a center that coordinates early intervention services in the state. Information can be obtained through NDSS and other organizations about the center nearest you. Public schools and community colleges are other resources. If there are no developmental centers in your area, many helpful books are available.

Who pays for early intervention?

The evaluation to determine whether your child is eligible for early intervention is free of charge if performed by a state authorized entity. No child deemed eligible can be denied services based on ability to pay, but insurance companies may be billed and/or a sliding scale payment may be required, depending in what state you reside. Check with your state's early intervention center for information about authorized service providers and financial obligations. Frequently, there is little or no cost to parents for these services.

