

A Promising Future Together

A Guide for New and Expectant Parents



national down syndrome society
ndss.[®]

The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities. We are committed to being the national advocate for the value, acceptance and inclusion of people with Down syndrome.

Dear Friends,

If you have recently given birth to, or are expecting, a baby with Down syndrome, you probably have many questions and concerns right now. You might be wondering, as I did when I was a new parent:

- How will Down syndrome affect my baby's development?
- What does the diagnosis mean for me as a parent?
- How will this newcomer affect the rest of my family?
- What is the best course to follow to help my baby reach his or her potential?
- What will he or she be like as a child, a teen and an adult?

My daughter Carson was born in 1978. I remember that as a new mother, the thing I wanted most was reassurance that my baby and family would be all right, but there was very little accurate information available to me at that time. As a direct result of my experience, I founded the National Down Syndrome Society to provide assistance to other families of individuals with Down syndrome. One of our first publications was a special booklet for new parents. It was filled with pictures of children with Down syndrome and featured quotes from parents about their experiences and hopes for the future.

All these years later, we are still providing up-to-date information about Down syndrome and sharing the message that your baby will develop in ways beyond your expectations. This guide for new and expectant parents includes information and tips to help you and your baby get off to the best start possible. It addresses topics related to health care, early intervention, and caring for yourself and your family. It also includes lists of resources that other parents have found helpful. We hope that this packet will provide you with the reassurance you might be searching for at this time.

Congratulations on the recent or upcoming birth of your baby, and may your new family member bring you the joy, love and laughter that Carson has brought to our family. Keep in mind that you are not alone. Although there will be challenges, an exciting journey lies ahead, and NDSS is here to provide information and support along the way.

Sincerely,



Elizabeth Goodwin
Founder
National Down Syndrome Society

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About Down Syndrome

Down syndrome is the most commonly occurring chromosomal condition. One in every 691 babies in the United States is born with Down syndrome. Down syndrome affects people in all races and economic levels. Today, individuals with Down syndrome are active participants in the educational, vocational, social and recreational aspects of our communities. Each year more teens and adults with Down syndrome are graduating from high school, going to college, finding meaningful employment and living independently. There are more opportunities than ever before for people with Down syndrome to develop their abilities, discover their talents and realize their dreams.

But what exactly is Down syndrome and how is it diagnosed? This section provides an overview of the genetics of Down syndrome and explains the various tests used for screening and diagnosis. It also discusses how Down syndrome can affect your baby's development.

What is Down syndrome?

The human body is made of cells. All cells contain a center, called a nucleus, in which genes are stored. Genes carry the codes responsible for all our inherited characteristics and are grouped along rod-like structures called chromosomes. The nucleus of each cell typically contains 23 pairs of chromosomes (half are inherited from the mother and half from the father). Down syndrome occurs when some or all of a person's cells have an extra full or partial copy of chromosome 21.

The most common form of Down syndrome is known as trisomy 21. Individuals with trisomy 21 have 47 chromosomes instead of the usual 46 in each of their cells. This condition results from an error in cell division called nondisjunction. Prior to or at conception, a pair of 21st chromosomes in either the sperm or the egg fails to separate, passing on both copies of the 21st chromosome instead of the typical one. As the embryo develops, the extra chromosome is replicated in every cell of the body. This error in cell division is responsible for 95% of all cases of Down syndrome.

The two other types of Down syndrome are called mosaicism and translocation. Mosaicism (or mosaic Down syndrome) occurs when nondisjunction of chromosome 21 takes place in one – but not all – of the initial cell divisions after fertilization. When this occurs, there is a mixture of two types of cells, some containing the usual 46 chromosomes and some containing 47. Those cells with 47 contain an extra chromosome 21. Mosaicism is the least common form of Down syndrome and accounts for only about 1% of all cases. Translocation, which accounts for about 4% of cases of Down syndrome, occurs when an additional full or partial copy of chromosome 21 breaks off during cell division and attaches to another chromosome, usually chromosome 14. While the total number of chromosomes in the cells remains 46, the presence of an extra full or partial chromosome 21 causes the characteristics of Down syndrome.

The cause of the extra full or partial chromosome is still unknown. It is not caused by environmental factors or anything the parents do before or during the pregnancy. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome resulting from nondisjunction or mosaicism. However, because younger women have higher fertility rates, 80% of babies with Down syndrome are born to women under the age of 35. Once a woman has given birth to a baby with Down syndrome, her chance of having a second child with Down syndrome is about 1 in 100, although age may also be a factor.

Maternal age, however, is not linked to the chance of having a baby with translocation. Most cases of translocation are chance events, just like trisomy 21 and mosaicism. About a third of cases of translocation (1% of all cases of Down syndrome) have a hereditary component – one unaffected parent is a carrier of a translocated chromosome. For this reason, the chance of translocation occurring in a second pregnancy is higher than the chance of nondisjunction occurring in a second pregnancy. Genetic counseling can determine if a parent is a carrier of the translocated chromosome.

What types of prenatal tests are available to detect Down syndrome?

There are two types of tests for Down syndrome that can be performed before your baby is born: screening tests and diagnostic tests. Prenatal screenings estimate the chance of the fetus having Down syndrome. These tests do not tell you for sure whether your fetus has Down syndrome; they only provide a probability. Diagnostic tests, on the other hand, can provide a definitive diagnosis with almost 100 percent accuracy.

There is an extensive menu of prenatal screening tests now available for pregnant women. Most of these screening tests involve a blood test and an ultrasound (sonogram). The blood tests (or serum screening tests) measure quantities of various substances in the blood of the mother, including alpha-fetoprotein, inhibin A, plasma protein A, estriol, and human chorionic gonadotropin. Together with a woman's age, these are used to estimate her chance of having a child with Down syndrome. Typically offered in the first and second trimesters, maternal serum screening tests are only able to predict about 80 percent of fetuses with Down syndrome. It is important to note that none of these prenatal screens will be able to definitively diagnose Down syndrome. Instead, mothers should expect results such as, "You have a 1 in 240 chance of having a child with Down syndrome" or "You have a 1 in 872 chance of having a child with Down syndrome."

These blood tests are often performed in conjunction with a detailed sonogram (ultrasound) to check for "markers" (characteristics that some researchers feel may have a significant association with Down syndrome). Recently, researchers have developed a maternal serum/ultrasound/age combination that can yield a much higher accuracy rate at an earlier stage in the pregnancy. Even with the ultrasound, however, the screening will not definitively diagnose Down syndrome.

In recent years, noninvasive prenatal screening tests, including "MaterniT21," have been made available. These tests, which can only be ordered through a physician, involve blood being taken from the expectant mother at as early as 10 weeks of gestation and rely on the detection of cell-free DNA that circulates between the fetus and the expectant mother. These blood tests can detect up to 98.6% of fetuses with trisomy 21. A "positive" result on the test means that there is a 98.6% chance that the fetus has trisomy 21; a "negative" result on the test means that there is a 99.8% chance that the fetus does not have trisomy 21. The turn-around time for the test is about 8-10 days, and approximately 0.8% of patients do not receive a result due to technical standards. While the initial clinical trials were conducted just on cases with trisomy 21, one form of Down syndrome, a "positive" result cannot distinguish between trisomy 21, translocation Down syndrome, and high-percentage mosaic Down syndrome. Put another way, a "positive" result will pick up all forms of Down syndrome, except mosaic Down syndrome that is 33% or lower. All mothers who receive a "positive" result on this test are encouraged to confirm the diagnosis with one of the diagnostic procedures described below.

Prenatal screening tests are now routinely offered to women of all ages. If the chance of having a child with Down syndrome is high from prenatal screening, doctors will often advise a mother to undergo diagnostic testing.

The diagnostic procedures available for prenatal diagnosis of Down syndrome are chorionic villus sampling (CVS) and amniocentesis. These procedures, which carry up to a 1% risk of causing a spontaneous termination (miscarriage), are nearly 100% accurate in diagnosing Down syndrome. Amniocentesis is usually performed in the second trimester between 15 and 22 weeks of gestation, and CVS in the first trimester between 9 and 14 weeks. Amniocentesis and CVS are also able to distinguish between these genetic types of Down syndrome: trisomy 21, translocation Down syndrome and mosaic Down syndrome.

Why should I get a prenatal test?

Some mothers choose to forgo all diagnostic testing because they know that they would continue their pregnancy no matter what and therefore do not want to expose their pregnancy to the small risk of miscarriage that comes with CVS and amniocentesis. Other mothers start with a prenatal screen then proceed to a definitive diagnostic test. Still other

mothers simply bypass the prenatal screening and start with a definitive diagnostic test. Whether or not to undergo prenatal screening or diagnostic testing is a personal decision, and expectant parents must make the choice that is best for them.

Some reasons for choosing a prenatal test include:

- **Advanced Awareness:** Some parents would like to know as soon as possible if their fetus has Down syndrome so that they can make preparations (like informing other family members and doing research on Down syndrome) prior to the birth. Families who have chosen this option have reported in research studies that the birth of their child with Down syndrome is as much of a celebratory process as any other birth because they have had time to adjust to the new diagnosis.
- **Adoption:** Some parents would like to receive a prenatal diagnosis so that they can make arrangements for adoption if their fetus has Down syndrome. There is a long waiting list of families in the United States ready to adopt a child with Down syndrome. For more information, visit the National Down Syndrome Adoption Network at www.ndsan.org.
- **Termination:** Some parents want to have a prenatal diagnosis so that they can discontinue their pregnancy. Parents should discuss this option with their obstetrician.

One of the best ways to begin to consider these choices is to speak to family members of individuals with Down syndrome through a local Down syndrome organization. In addition, there are many books and articles written by family members about their personal experiences. A message from families that is echoed again and again is that the positive impacts of having a member with Down syndrome far outweigh any difficulties or challenges that may come up. If you have any questions about these procedures, do not hesitate to ask your doctor. It is important that you receive accurate information and understand all your options.

How is Down syndrome diagnosed?

Since many expectant parents choose to forgo prenatal tests, most cases of Down syndrome are diagnosed after the baby is born. Doctors will usually suspect Down syndrome if certain physical characteristics are present. Some of the traits common to babies with Down syndrome include:

- *low muscle tone*
- *a flat facial profile*
- *a small nose*
- *an upward slant to the eyes*
- *a single deep crease across the center of the palm*
- *an excessive ability to extend the joints*
- *small skin folds on the inner corner of the eyes*
- *excessive space between large and second toe*

Not all babies with Down syndrome have all these characteristics, and many of these features can be found, to some extent, in individuals who do not have the condition. Therefore, doctors must perform a special test called a karyotype before making a definitive diagnosis.

To obtain a karyotype, doctors draw a blood sample to examine your baby's cells. They use special tools to photograph the chromosomes and then group them by size, number and shape. By examining the karyotype, they can determine accurately whether or not your baby has Down syndrome.



How will Down syndrome affect my baby's development?

An additional chromosome means that there is excess genetic material in your baby's cells. While this will affect your child's development, it is important to realize that it is not a blueprint that determines his or her potential. Down syndrome is a condition your child has – it's not who your child is. As is true for all people, the skills and knowledge he or she acquires will be a unique combination of innate abilities and life experiences.

In most ways, your baby will be just like other infants. Every baby needs to be fed, held, and most of all, loved. There are, however, certain health and developmental concerns commonly associated with Down syndrome. Individuals with Down syndrome are at an increased risk for certain health conditions. Babies, in particular, are more likely to have heart problems, hearing loss and respiratory infections; however, advances in medicine have rendered the majority of these health problems treatable.

All people with Down syndrome experience delays in their cognitive and physical development, however, cognitive delays are usually mild to moderate, and they are not indicative of the many strengths and talents that each individual possesses. Low muscle tone and other physical characteristics associated with Down syndrome can affect how soon your baby will be able to sit up, walk and speak. Rest assured, though, your child will learn to do these and many more activities, only possibly somewhat later than his or her peers without Down syndrome.

Good medical care and early intervention can provide a strong foundation for your child's optimal development. The next two sections, "A Healthy Start" and "Early Intervention," will help you begin learning about what you can do to help your baby get off to the best start possible!

Additional Resources

BOOKS

Babies with Down Syndrome: A New Parents' Guide (Third Edition). Skallerup, S. (Ed.) (2008). Bethesda, MD: Woodbine House.

This hugely popular and well regarded book addresses the medical, emotional, educational and social issues that may arise when parenting a baby with Down syndrome.

Available from Woodbine House at www.woodbinehouse.com or 800-843-7323

A Parent's Guide to Down Syndrome: Toward a Brighter Future. Pueschel, S. (2000). Baltimore, MD: Brookes Publishing.

Written especially for new parents, this book addresses the medical, emotional, educational and social issues related to Down syndrome.

Available from Brookes Publishing at www.brookespublishing.com or 800-638-3775

DVDS

Down Syndrome: The First 18 Months. Blueberry Shoes Productions.

A comprehensive overview of what to expect and do for babies with Down syndrome from birth to walking.

Available from Blueberry Shoes Productions at www.blueberryshoes.com or 703-335-1776

ORGANIZATIONS

International Mosaic Down Syndrome Association
www.imdsa.org

Offers support and resources to families of and individuals with mosaic Down syndrome through the lifespan

National Society of Genetic Counselors
www.nsgc.org

Find members of NSGC through the "Find a Genetic Counselor" search.

WEBSITES

Brighter Tomorrows
www.brightertomorrows.org

Brighter Tomorrows is a web-based resource for parents who have received a diagnosis of Down syndrome either prenatally or at birth. The site provides answers to common questions, educates about Down syndrome and shares the stories of other parents in similar situations.

Down Syndrome Pregnancy
www.downsyndromepregnancy.org

This site provides information and support to expectant parents preparing for the birth of a baby with Down syndrome.

Medline Plus: Health Topics - Down Syndrome
www.nlm.nih.gov/medlineplus/downsyndrome.html

This is an overview and list of resources on Down syndrome and prenatal testing from Medline Plus, a service of the US National Library of Medicine and the National Institutes of Health.

The books, DVDs, organizations and websites listed throughout this guide are just a sample of the resources available for families of children with Down syndrome. Contact NDSS for further resources.





A Healthy Start

One of the main questions on the minds of many new parents is, “Will my baby be healthy?” Many babies with Down syndrome are born without any health problems. However, it is true that newborns with Down syndrome are at a higher risk for certain complications. While your baby may not have any of these potential complications, it is important to be aware of them so you can catch them early if they do occur. This section discusses possible health concerns and useful tools for monitoring your child’s health care and growth patterns. It also provides information on how to select a pediatrician, questions to think about when making decisions about potential treatments, and a discussion of feeding options.

What health conditions are associated with Down syndrome?

Newborns with Down syndrome are at a higher risk for congenital heart defects, hearing and vision loss, respiratory problems, obstructed digestive tracts, childhood leukemia, and other health conditions. They also have an increased susceptibility to infection. Doctors routinely screen for these conditions because some, such as a heart defect, may be present even if no symptoms are readily apparent. While the list of possible health problems can be frightening, keep in mind that your baby will not necessarily have all, or possibly any, of them. If he or she does happen to have one or more of these complications, advances in medicine have rendered most conditions treatable. For instance, the majority of heart conditions can be corrected through surgery.

You can ensure your newborn’s optimal development through informed health care. There is a tremendous amount of information available, so it is important not to let yourself get overwhelmed. Learn at your own pace, and try to focus on those things you can do in the present to get your baby off to a good start. The Health Care Guidelines for Individuals with Down Syndrome can be helpful. Copies of these documents are included in the back of this booklet.

What are the Down Syndrome Health Care Guidelines?

The Down Syndrome Health Care Guidelines follow an individual’s development from birth through adulthood and provide information about potential health concerns at each stage. They are compiled by the Down Syndrome Medical Interest Group, a national affiliation of health care providers who specialize in caring for individuals with Down syndrome.

These guidelines help define the standards of quality care for individuals with Down syndrome. In addition to specific recommendations for screening tests, they include information about the kinds of medical conditions that individuals with Down syndrome are at risk for and suggestions for early intervention, diet and exercise, and other issues across the lifespan.

You can use the Health Care Guidelines to ensure that your baby is up to date on required and recommended screenings. While your pediatrician may be knowledgeable about the current recommendations, it is a good idea to provide him or her with a copy to place in your child’s file. In addition to being in the back of this booklet, the Health Care Guidelines can be printed and downloaded from the “Health Care” section of www.ndss.org.

Because you are ultimately the most concerned with your child’s development, it is important for you to become familiar with the guidelines and communicate on a regular basis with your physician to make sure your baby is getting the best care possible.



Specialized Health Information

The NDSS website, www.ndss.org, is a comprehensive and up-to-date resource for families. It provides overviews of health and developmental concerns in individuals with Down syndrome.

What should I look for in a pediatrician?

For optimal health care, it makes sense to locate a developmental pediatrician or a specialist knowledgeable about Down syndrome, if any are available in your area. You can also contact NDSS to learn the location of the nearest Down syndrome specialty clinic. However, keep in mind that it is not always necessary to find an expert on Down syndrome. The most important thing to consider when you have a baby with special health care needs is finding a doctor who is willing to learn about the condition and collaborate with you to ensure the best possible care for your child.

One of the best ways to find a pediatrician is to ask families of other children with Down syndrome in your area for recommendations. Local parent support groups can be a good source of referrals. Contact NDSS to find your local parent support group. As a parent, you have a right to interview potential physicians to find the best one for you. Find someone you feel comfortable with and with whom you can communicate freely. Also, do not be intimidated when speaking to physicians. A good doctor recognizes that parents are experts when it comes to their children. He or she respects their concerns and sees them as partners.

Down Syndrome Clinics

Down syndrome clinics provide specialized medical care and other services for individuals with Down syndrome and their families.

To learn if there is a Down syndrome clinic near you, contact NDSS at 800-221-4602 or info@ndss.org.

You can also see a list of Down syndrome clinics across the country at www.ndss.org, in the “Health Care” section.

What about alternative therapies?

As a parent, you no doubt want to give your child every opportunity to realize his or her life aspirations and lead a fulfilling life. You will likely come across lots of information about various alternative therapies as you research Down syndrome. Parents often get excited about claims that particular treatments can improve motor and cognitive functions or other areas of development, and many invest a lot of hope and money in these treatments. While this is understandable, be aware that although there have been many popular therapies through the years, none have been scientifically proven. In fact, some have been proven ineffective or even harmful.

When considering any potential therapy, be sure to discuss it with your pediatrician. Ask for copies of current research studies that support the therapy's claims and consider the following questions:

- *Is the therapy documented as safe and effective?*
- *Are the claims realistic?*
- *What are the credentials and background of the person promoting the therapy? (For example, is he or she certified by a professional organization?)*
- *Does the person have financial interests in the sale of the therapy?*
- *Is the therapy expensive or overly demanding of your family's time?*
- *What are the risks and side effects, and do they outweigh the potential benefits?*

You can contact NDSS for further information about alternative therapies and our position statements on specific treatments.





Should I breastfeed or bottlefeed my baby with Down syndrome?

You may be aware of the tremendous benefits that breastfeeding provides to newborns. Breastmilk contains natural antibodies that fortify babies' immune systems. This is especially important to infants with Down syndrome, who have higher rates of respiratory and other infections. Breastmilk can also reduce bowel problems, which are more common in babies with Down syndrome, and contains an ingredient known to promote brain growth and development.

In addition, the physical process of breastfeeding strengthens babies' jaw and facial muscles, which helps lay a good foundation for speech and language development, and provides skin-to-skin contact, a form of sensory stimulation that creates neural connections that can facilitate future learning.

There are many great reasons to breastfeed, but whether or not to do so is a personal choice. Some mothers breastfeed exclusively while others bottlefeed. Still others combine the two. There are many factors that play into this decision, including whether or not you feel your body is producing enough milk, whether or not your baby has health complications, and whether or not you plan to return to work soon after delivery.

If you do plan to breastfeed, be aware of certain factors that might make it challenging. Babies with Down syndrome have low muscle tone, so it may be difficult for your baby to "latch on" to your breast at first. As babies with Down Syndrome also tend to be sleepier than other infants, you will likely have to make an extra effort to raise your baby's alertness and keep him or her awake throughout the entire feeding. Also, if your baby needs surgery, he or she may require a feeding tube for a short time.

Don't worry, though. There are many organizations and individuals that can help you get started and provide tips for overcoming these and any other challenges you may encounter. These same specialists can help you learn how to pump, store and transport your breastmilk or how to select the right baby formula to meet your infant's needs if you choose to bottlefeed.

When it comes to feeding, the important thing is to make the choice that is best for you. Feedings should provide quality time for a parent and child to bond, so they should always be as comfortable and stress-free as possible for both individuals. A meeting with your hospital's lactation specialist is a great place to start learning about what feeding option may be right for you.

Additional Resources

BOOKS

The Down Syndrome Nutrition Handbook.
Guthrie Medlen, J. (2006).
Lake Oswego, OR: Phronesis Publishing.

This comprehensive guide for educating children and adults with Down syndrome about nutrition and healthy lifestyles covers nutrition issues from birth to adulthood. It includes a chapter on breast and bottle feeding infants.

Available from Phronesis Publishing at
www.downsyndromenutrition.com

DVDS

Kids with Down Syndrome: Staying Healthy and Making Friends.
Blueberry Shoes Productions.

This video brings together parents and professionals to discuss such topics as toilet training, nutrition, hearing, sleep issues, exercise, conversation skills, friendship and behavior.

Available from Blueberry Shoes Productions
at www.blueberryshoes.com
or 703-335-1776

ORGANIZATIONS

Australian Breastfeeding Association
Email: info@breastfeeding.asn.au
Website: www.breastfeeding.asn.au

The Australian Breastfeeding Association works to provide accurate and helpful information to women who are interested in learning more about breastfeeding, as well as assistance to women who are currently breastfeeding. ABA has a section of their website dedicated to breastfeeding children with Down syndrome at www.breastfeeding.asn.au/bf-info/down

La Leche League International
Telephone: 800-525-3243
Website: www.lalecheleague.org

La Leche League was founded to give information and encouragement, mainly through personal help, to all mothers who want to breastfeed their babies. While complementing the care of the physician and other health care professionals, it recognizes the unique importance of one mother helping another to perceive the needs of her child and to learn the best means of fulfilling those needs. La Leche League has information specific to breastfeeding children with Down syndrome at www.lalecheleague.org/FAQ/down.html

The books, DVDs, organizations and websites listed throughout this guide are just a sample of the resources available for families of children with Down syndrome. Contact NDSS for further resources.





Early Intervention

The first years of life are a critical time in a child's development. All young children go through their most rapid and developmentally significant changes during this time. During these early years they achieve the basic physical, cognitive, language, social and self-help skills that lay the foundation for future progress. These abilities are attained according to predictable developmental patterns. Children with Down syndrome typically face delays in certain areas of development, so early intervention is highly recommended. It can begin anytime after birth but the earlier it starts, the better. This section provides details on the types of early intervention available and how to access services.

What is early intervention?

Early intervention is a systematic program of therapy, exercises and activities designed to address any developmental delays that may be experienced by children with Down syndrome or other disabilities. These services are mandated by a federal law called the Individuals with Disabilities Education Act (IDEA). This law requires that states provide early intervention services for all children who qualify, with the goal of enhancing the development of infants and toddlers and helping families understand and meet the needs of their children. The most common early intervention services for babies with Down syndrome are physical therapy, speech and language therapy, and occupational therapy.

When should early intervention start?

Early intervention should begin any time shortly after birth and usually continues until the child reaches age 3. An amendment to IDEA in 2004 allows states to have early intervention programs that may continue until the child enters, or is eligible to enter, kindergarten. The sooner early intervention begins, the better; however, it's never too late to start.

How can early intervention benefit my baby?

Development is a continuous process that begins at conception and proceeds stage by stage in an orderly sequence. There are specific milestones in each of the four areas of development (gross and fine motor abilities, language skills, social development and self-help skills) that serve as prerequisites for the stages that follow. Most children are expected to achieve each milestone at a designated time, also referred to as a "key age," which can be calculated in terms of weeks, months or years. Because of specific challenges associated with Down syndrome, your baby will likely experience delays in certain areas of development. Rest assured that he or she will achieve each of the same milestones as other children, just on his or her own timetable. In monitoring the development of your child with Down syndrome, it is useful to focus on the sequence in which milestones are achieved rather than the age at which they are achieved.



What types of early intervention address each type of development?

Physical therapy focuses on motor development. For example, during the first 3 to 4 months of life, an infant is expected to gain head control and the ability to pull to a sitting positions (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.

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, reach and grasp toys, turn one's head in order to follow a moving object with one's eyes, roll over, crawl in pursuit of a desired objective - all of these behaviors are dependent upon gross as well as fine motor development. These physical, interactive activities foster understanding and mastery of the environment, stimulating cognitive, language and social development.

"Early intervention was definitely helpful to her development and to mine. It motivated us to do all we could to help her reach her potential. It was a learning time for both of us."

Another long term benefit of physical therapy is that it helps prevent compensatory movement patterns that individuals with Down syndrome are prone to developing. Such patterns can lead to orthopedic and functional problems if not corrected.

Speech and language therapy is a critical component of early intervention. Even though babies with Down syndrome may not say first words until 2 or 3 years of age, there are many pre-speech and pre-language skills that must be acquired first. These include the ability to imitate and echo sounds; turn taking skills (learned through games like "peek-a-boo"); visual skills (looking at speakers and objects); auditory skills (listening to music and speech for lengthening periods of time); tactile skills (learning about touch, exploring objects in the mouth); oral motor skills (using the tongue, moving the lips); and cognitive skills (understanding object permanence and cause and effect relationships).

A speech and language therapist can help with these and other skills, including breastfeeding. Because breastfeeding employs the same anatomical structures used for speech, it can help strengthen a baby's jaw and facial muscles and lay the foundation for future communication skills.

Occupational therapy helps children develop and master skills for independence. Occupational therapy can help with abilities such as opening and closing things, picking up and releasing toys of various sizes and shapes, stacking and building, manipulating knobs and buttons, experimenting with crayons, etc. Therapists also help children learn to feed and dress themselves, and teach skills for playing and interacting with other children.

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.

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 infants and toddlers, how to meet their children's specific needs and how to enhance development.

How do I sign up for early intervention services?

Each state has its own set of laws governing early intervention services. You can get a referral from your baby's doctor or find a local agency by visiting www.ectacenter.org. Once a referral has been made, the program staff must schedule and complete an initial evaluation within a specified time. Once the assessment is done, a caseworker will be assigned to coordinate the various services for which your baby and family qualifies. Early intervention services are individualized to meet the specific needs of each individual baby. The caseworker, therapists and family will determine the areas of focus and set goals based on the developmental milestones. These will be recorded in a document called the Individualized Family Service Plan, or IFSP.

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 on what state you reside in. 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.

What happens after age 3?

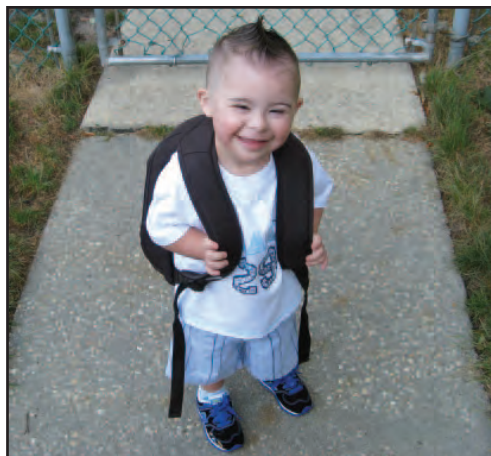
IDEA, which regulates early intervention, also mandates that local school districts provide a free, appropriate, public education for preschool-age children with disabilities starting at the age of 3, unless that would be inconsistent with state law or practice, or the order of any court, respecting the provision of public education to children between the ages of 3 and 5.



"His eyes would light up when he got something right. You just fill up with love and accomplishment at a moment like that."

Milestone	Range for Children with Down Syndrome	Typical Range
GROSS MOTOR		
Sits Alone	6 – 30 Months	5 – 9 Months
Crawls	8 – 22 Months	6 – 12 Months
Stands	1 – 3.25 Years	8 – 17 Months
Walks Alone	1 – 4 Years	9 – 18 Months
LANGUAGE		
First Word	1 – 4 Years	1 – 3 Years
Two-Word Phrases	2 – 7.5 Years	15 – 32 Months
SOCIAL/SELF-HELP		
Responsive Smile	1.5 – 5 Months	1 – 3 Months
Finger Feeds	10 – 24 Months	7 – 14 Months
Drinks From Cup Unassisted	12 – 32 Months	9 – 17 Months
Uses Spoon	13 – 39 Months	12 – 20 Months
Bowel Control	2 – 7 Years	16 – 42 Months
Dresses Self Unassisted	3.5 – 8.5 Years	3.25 – 5 Years

“You have to forget the timetable you reserve for your other kids. This child will succeed at his own pace.”



Additional Resources

BOOKS

Early Communication Skills for Children with Down Syndrome.

Kumin, L. (2003).

Bethesda, MD: Woodbine House.

A comprehensive look at the role of a speech language pathologist, how certain characteristics of Down syndrome affect speech and language development, and the stages of communication development.

Available from Woodbine House at www.woodbinehouse.com or 800-843-7323

Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals (Second Edition).

Bruni, M. (2006).

Bethesda, MD: Woodbine House.

An explanation of the best practices and procedures for helping children master daily living skills for home, school and an independent future.

Available from Woodbine House at www.woodbinehouse.com or 800-843-7323

Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals.

Winders, P. (1997).

Bethesda, MD: Woodbine House.

This guide provides parents and professionals with essential information about motor development. Over 100 activities and accompanying photos make it easy to practice motor skills with infants and children through age 6.

Available from Woodbine House at www.woodbinehouse.com or 800-843-7323

The New Language of Toys: Teaching Communication Skills to Special- Needs Children (Third Edition).

Schwartz, S. (2004).

Bethesda, MD: Woodbine House.

This book presents a language learning program based on play, and explains how parents can stimulate their child's learning development through fun and educational exercises involving toys.

Available from Woodbine House at www.woodbinehouse.com or 800-843-7323

Teaching Reading to Children with Down Syndrome: A Guide For Parents and Teachers.

Oelwein, P. (1995).

Bethesda, MD: Woodbine

This is a step-by-step reading program specifically tailored to children with Down syndrome, with an emphasis on visual learning.

Available from Woodbine House at www.woodbinehouse.com or 800-843-7323

DVDS

Emma's Gifts.

Endless Horizon Productions.

This documentary follows one family's journey through the preschool years, illustrating the power of advocating for a child's rights and the importance of early intervention. Emma's parents share their stories to provide a very touching, realistic view of having a child with Down syndrome. Includes Emma's speech evaluation and a photo album.

Available from Endless Horizon Productions at www.emmasgiftsfilm.com or email endlesshorizonproductions@gmail.com

Signing Time

www.signingtime.com

Based around a popular series of sign language DVDs, this website offers online resources for parents whose children are learning to sign. It also features a variety of educational products for sale, including some designed specifically for children with Down syndrome.

ORGANIZATIONS

Division for Early Childhood of the Council for Exceptional Children

Telephone: 406-543-0872

Email: dec@dec-sped.org

Website: www.dec-sped.org

One of 17 divisions of the Council for Exceptional Children, this organization supports policies and practices that support families and enhance development in especially young children with disabilities and learning delays.

Early Childhood Outcomes Center

Email: staff@the-eco-center.org

Website: www.the-eco-center.org

The ECO Center promotes the development of progress reports for young children with disabilities and the implementation of these reports on a local, state, and national level.

Early Childhood Technical Assistance Center (ECTAC)

Telephone: 919-962-2001

Email: nectac@unc.edu

Website: www.nectac.org

NECTAC supports the national implementation of the Individuals with Disabilities Education Act (IDEA) by working with each state to provide technical assistance for children with disabilities and their families. The website provides a list of early intervention programs by state.

ALLIANCE National Parent Technical Assistance Center

Telephone: 888-248-0822

Email: alliance@taalliance.org

Website: <http://www.parentcenternetwork.org/national>

Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) in each state provide training and information to parents of infants, toddlers, children, youths with disabilities and professionals who work with them. The website provides a list of centers by state.

WEBSITES

Education Resources Information Center (ERIC) Database

www.eric.ed.gov

Sponsored by the Institute of Education Sciences of the U.S. Department of Education, this is a free online digital library of journal and non-journal education literature.

The books, DVDs, organizations and websites listed throughout this guide are just a sample of the resources available for families of children with Down syndrome. Contact NDSS for further resources.



Finding Support

If you have recently learned that your baby has or will have Down syndrome, you probably have a million questions, concerns and fears right now. That's okay. The most important thing to keep in mind is that the diagnosis is not as life-changing as the fact that you have a new baby. There will be challenges in raising your child, but there will also be many, many joys. This section discusses some of the sources you can turn to for support and reassurance at this time.

Is what I'm feeling normal?

Learning that your baby has Down syndrome is not an easy thing for anyone to face, and right now, you may be experiencing a roller coaster of emotions. While everyone handles the diagnosis in their own way, certain reactions are common in new or expectant parents of a child with a disability. For the majority of parents, the period immediately following the diagnosis is filled with uncertainty and doubt. For example, you might worry about how the condition will impact your child's life and whether or not you are equipped to handle all the responsibilities of raising a child with a disability. If your child has health complications, you may have additional fears and concerns. It is natural to experience denial, anger, depression and other stages of grief as you adjust to the news that your baby has Down syndrome. Even for parents who knew they were at a higher risk of having a child with Down syndrome or have received a positive diagnosis, acceptance can be difficult or, at first, seem impossible.

Know that whatever you may be feeling is normal. More importantly, know that you are not alone. Many sources of support are available to new or expectant parents of children with Down syndrome. In time, and with the right support, you can expect the intensity of painful emotions to subside and new, positive feelings to take their place. One of the best places to turn to for encouragement and reassurance is other parents of children with Down syndrome. Often, other parents can help you look beyond your baby's diagnosis and find delight in the joys of parenthood. They have been through what you are going through, and can be an invaluable source of support.

How can I get in touch with other parents of children with Down syndrome?

One of the best ways to meet other parents is to get involved in a local Down syndrome parent support group. These groups can provide you with an excellent forum for sharing your feelings and concerns as a new parent, and an opportunity to learn from the experiences of others who have been in your shoes. Learning more about Down syndrome can also help ease some of your uncertainty, and support groups are a great place to start gaining knowledge. In addition to providing emotional support, other parents can recommend useful Down syndrome resources and organizations and help you understand the new terminology.

NDSS has a network of more than 350 affiliate parent support groups, and we can refer you to the group closest to your home. You can call or email our Goodwin Family Information and Referral Center to get this information. In addition to holding support group meetings, most of our affiliates offer a wide range of other programs and services for individuals with Down syndrome and their families, such as sibling workshops, expert speaker presentations, early intervention programs, social activities, and events to raise public awareness. Support group membership can provide benefits to you and your family now and in the future, so we encourage you to contact your local group and explore this option.



If there is not a Down syndrome-specific support group in your area, your hospital or pediatrician may be able to provide contact information for other parents who have agreed to serve as a resource. There may also be a general support group for parents of children with disabilities that you can join. Alternately, you may consider starting your own support group to network with others. NDSS can provide you with the information you need to get started.

"We have become wonderful friends with other parents from our support group. Initially, it was just comforting to be with other people who were walking in our shoes and learning with us. We didn't have to explain our feelings or hide them."

What are some other things I can do to take care of myself?

Right now, you are very focused on taking good care of your baby. But remember, it's also important to take good care of yourself at this time. Doing so will keep you feeling healthy, strong and well-equipped to deal with your responsibilities as a parent. It can also help you develop and maintain a positive frame of mind, which is necessary for meeting new challenges successfully. Here are some tips many new parents have found helpful for reducing anxiety and stress:

Be patient with yourself. The road to acceptance is a process, so give yourself time to deal with your emotional responses. Some days you might feel like you're taking steps backward, but recognize that this doesn't mean you aren't making progress. If you feel it would be helpful, do not hesitate to contact a therapist. A therapist can help you find ways to cope and develop confidence in your ability to handle challenges.

Build a support system. It may be tempting to keep to yourself at this time, but doing so can result in feelings of isolation. Reach out to trusted friends or family members. This allows your loved ones to understand what you're going through and gives them a chance to offer comfort and support. You can always let them know how much help you need or desire, and if you want time alone, don't hesitate to say so.

Schedule some alone time regularly, and use this time to "recharge." Read a book, take a warm bath, go for a walk, or just watch your favorite TV show. Do something you enjoy and find relaxing, and let yourself enjoy it. Alone time may sound like a luxury, but it is necessary for good health and can do wonders for your productivity and mood.

Take care of your physical health. Research shows that a healthy eating and exercise plan can reduce fatigue, irritability, and risk for certain diseases and health complications. Develop a plan that works for you and make an effort to stick to it, especially during times of high stress. Be sure to get regular medical check-ups, too.

Practice living in the moment. While it is important to plan ahead, worrying about the future can easily lead to anxiety. Although it may be hard, try to focus only on what you can do realistically in the present. If you find yourself getting anxious about a particular situation, try this strategy:

- 1) *Identify the problem.*
- 2) *Research your options.*
- 3) *Make a decision.*
- 4) *Set a date in the future to evaluate how your decision is working.*

"My son has helped me to grow as an individual, be more aware of others, and see what is really important in life. He has taught me the beauty of unconditional love."

In the meantime, just go with the decision you made and trust that everything will work out.

Don't lose sight of "the important things in life." Nurture your relationships with your partner, children, friends and family. Communicate with each other, laugh, do fun things together, celebrate traditions and be sure to spend quality time with your new baby that doesn't focus on his or her disability. The fact that your baby has Down syndrome is life-changing. But it doesn't change the things that are truly important in life!



A Parent's Perspective on Having a Child With a Disability

Welcome to Holland

By Emily Perl Kingsley

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I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around ... and you begin to notice Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy ... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away ... because the loss of that dream is a very, very significant loss.

But...if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.



Additional Resources

BOOKS

Common Threads: Celebrating Life with Down Syndrome.
Kidder, C., Skotko, B., and Dew, K. (2007).
Rochester Hills, MI: Band of Angels Press.

Band of Angels demonstrates how the similarities outweigh the differences between children with Down syndrome and their peers.

Available from Band of Angels Press at www.bandofangels.com or 800-963-2237

Count Us In: Growing Up with Down Syndrome.
Kingsley, J. and Levitz, M. (2007).
New York, NY: Mariner Books.

Two men give intimately personal accounts of their lives with Down syndrome. Topics discussed include friendship, school, and independence.

Available from Houghton Mifflin Company at www.hmhbooks.com

Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives.
Soper, K. (Ed.) (2007).
Bethesda, MD: Woodbine House

A touching compilation of mothers' accounts, Gifts centers on the joys their children with Down syndrome bring to their lives.

Available from Woodbine House at www.woodbinehouse.com or 800-843-7323

Gifts 2: How Children with Down Syndrome Enrich the World.
Soper, K. (Ed.) (2009).
Bethesda, MD: Woodbine House.

The second volume in this series recounts stories of other family members as well as mother's of older children which highlight the way children with Down syndrome can bring happiness and pride to their families and communities.

Available from Woodbine House at www.woodbinehouse.com or 800-843-7323

More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs.
Baskin, A. and Fawcett, H. (2007).
Bethesda, MD: Woodbine House.

This book offers useful advice, hints and wisdom for managing daily life as a parent of a child with special needs.

Available from Woodbine House at www.woodbinehouse.com or 800-843-7323

Road Map to Holland: How I Found My Way Through My Son's First Two Years with Down Syndrome.

Graf Groneberg, J. (2008).
New York, NY: New American Library.

A mother's very personal account as she continues to struggle to find balance in the hardships and joys of raising a child with special needs.

Available from New American Library at www.us.penguingroup.com

A Special Kind of Hero; Chris Burke's Own Story (Second Edition).
Burke, C. and McDaniel, J.B. (2001).
Lincoln, NE: iUniverse.com

In his widely acclaimed and inspirational autobiography, Actor and Goodwill Ambassador Chris Burke shares his struggles growing up with Down Syndrome and the unshakable spirit of optimism that helped him achieve unheard success in show business as "Corky" in the TV series *Life Goes On*.

Available from Barnes & Noble at www.barnesandnoble.com

ORGANIZATIONS

D.A.D.S. (Dads Appreciating Down Syndrome)

Email: info@dadsnational.org
Website: www.dadsnational.org

An organization of fathers of children with Down syndrome, D.A.D.S. has an extensive network that includes chapters throughout the country and an online forum.

Little Hearts

Telephone: 866-435-4673
Website: www.littlehearts.org

Little Hearts is a national organization providing support, education, resources, networking, and stories of hope to families of children affected by congenital heart defects.

Parent to Parent USA

Email: memberinfo@p2pusa.org
Website: www.p2pusa.org

Parent to Parent programs across the country provide emotional and informational support to families of children who have special needs most notably by matching parents seeking support with an experienced, trained "Support Parent."



The books, DVDs, organizations and websites listed throughout this guide are just a sample of the resources available for families of children with Down syndrome. Contact NDSS for further resources.



Caring For Your Family

It's natural for new parents of a child with Down syndrome to wonder how this new person will impact family members and relationships. You might be asking yourself: How will having a brother or sister with Down syndrome affect my other children? Will having a child with a disability alter my relationship with my partner? How will my relationships with friends and relatives change? While each family's situation is unique, it may be helpful and encouraging to know that both personal accounts and research studies provide solid evidence that families of children with Down syndrome can be stable, successful and happy. This section provides information on what you can do to meet the needs of your entire family.

How will having a baby with Down syndrome affect my family?

One of the best ways to find an answer to this question is by speaking to family members of individuals with Down syndrome. In addition, there are many books and articles written by family members about their personal experiences. A message you'll encounter time and time again is that the positive impacts of having a family member with Down syndrome far outweigh any difficulties or challenges that may come up. The majority of families share that they are stronger and closer as a result of the experience of dealing with a disability, and that they are more focused on the things that really matter in life.

There have also been many research studies that explore how having a child with Down syndrome affects families. These have shown that while these families do experience additional challenges, their levels of well-being are comparable to those of families who do not have a child with Down syndrome. Researchers say that what seems to determine if families are resilient and able to thrive is their ability to access individual, family and community resources. By contacting NDSS, you have taken an important first step in ensuring that your family has the support it needs to adapt successfully and stay strong. Be sure to also take advantage of all the resources available in your local community, and focus on building a support network to get you and your family through any tough times.

How will having a sibling with Down syndrome affect my other children?

While having a sibling with Down syndrome may present unique challenges, it also provides many opportunities for children's positive growth and character development. Studies have shown that children who have a brother or sister with Down syndrome can benefit in many ways. For example, these children often exhibit a level of maturity above that of their peers and tend to have more highly-developed communication and social skills. The experience and knowledge gained by having a sibling with Down syndrome also seems to make children more accepting and appreciative of differences. They tend to be more aware of the difficulties that others might be going through, and often surprise parents, teachers and others with their wisdom, insight and empathy.

Brothers and sisters of individuals with Down syndrome are also very much aware of their sibling's challenges and thus, often take a tremendous amount of pride in his or her accomplishments. In addition, parents often report that, no matter what issues siblings may have with their brother or sister with Down syndrome at home, outside the home they are typically very loyal to their sibling and do their best to defend and protect him or her.

How do I explain Down syndrome to my other children?

When telling your children that their new little brother or sister has Down syndrome, tailor your explanation to their age and ability to comprehend. An older child might be able to understand the genetics of Down syndrome, while a younger sibling might need a simpler explanation. Encourage your children to ask questions about whatever they don't understand and be sure to emphasize that the new baby will be able to do all the same things other babies do. Most children are able to grasp that a baby with Down syndrome may learn a little more slowly and need extra care, and they often take special pride in helping their new sibling.

Remember that your children will take their cue from you. If you are able to communicate excitement about their new sibling, they will be excited, too. Try to keep up family routines and traditions, and don't curb family activities in the community any more than is necessary. This will help your other children come to terms with their sibling's condition while giving your new baby many new varied experiences. Brothers and sisters are often the first to realize that their new sibling is more like other kids than different, with his or her own unique personality, and that like all members of the family, he or she will have strengths, challenges and much to contribute.

"We were both afraid of how our new baby would affect our family. As it turns out, she is the light of our lives."

What are some tips for taking care of my other children's needs?

As discussed, your children may be doing an excellent job of helping with their brother or sister, but you want to make sure you are doing all you can to meet their needs as well. Here are some tips for caring for siblings:

- *Be sure to acknowledge all emotions, not just the positive ones. If your children know that it is okay to express any feelings they may be having about their sibling with Down syndrome, negative emotions are less likely to turn up in other ways, such as behavior problems.*

"My sister has taught me more about life and how to live it than anybody. She motivates me because I know how hard she works."





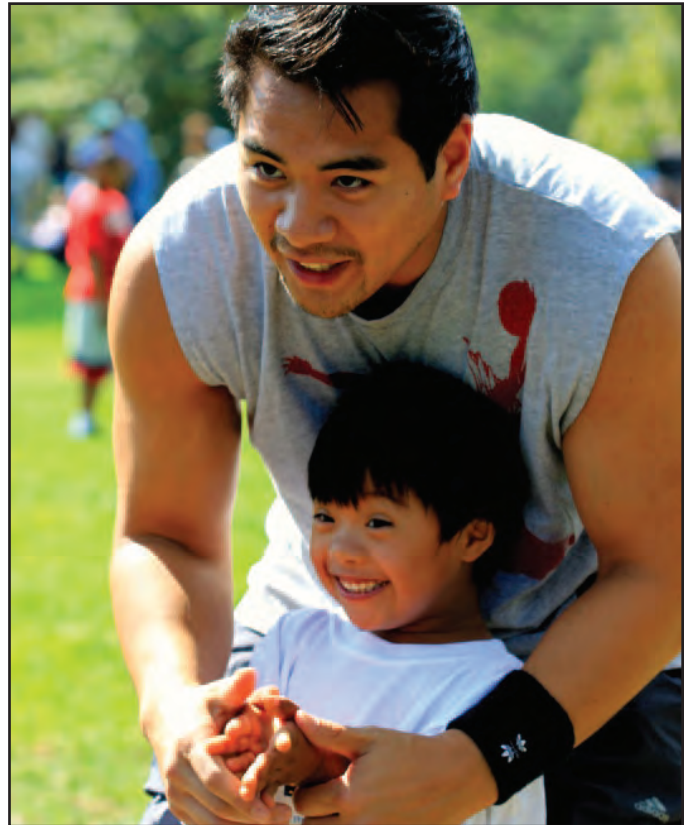
- While it can be beneficial for your other children to feel they can play an important role in caring for their sibling with Down syndrome, don't give them too many responsibilities in this area.
- Although your responsibilities may pull you in many different directions, pay attention to your children and any changes in their moods. If you notice symptoms of anxiety or depression, get your child the help he or she needs as early as possible.
- Make an effort to spend time with each of your children on a regular basis. Each child is unique, so don't worry about dividing your time equally. Instead, focus on what's important to an individual child, and dedicate time to those things that would make him or her feel loved and special. Remind your children that all members of your family are special in their own way.

How can I keep my relationship with my partner strong?

There are many things you can do to keep your relationship strong amidst the added stresses that may come when raising a child with a disability. Two key strategies often mentioned by parents are maintaining good communication and spending time alone together. So take a few minutes every day to talk with your partner. Plan a regular "date night." Or, take a vacation together. Even if you can't get away as often as you might like, make an effort to keep your romance alive. Don't let anniversaries or other special occasions go uncelebrated, and do little things to show your partner that you care and appreciate all of his or her hard work.

"I actually think having a child with Down syndrome has strengthened our relationship. We are in this together."

A loving relationship is one of the best sources of strength and support for dealing with any challenges that come your way.



How do I share the diagnosis with other family members and friends?

New parents sometimes worry about telling friends and family members about their baby's condition. However, it is recommended that you do it as early as possible. Parents report that the longer you wait, the harder it gets. Not only will waiting add to the stress that you may already be dealing with, but you will likely miss out on the comfort and support your loved ones might be able to provide during this time. Keep in mind, too, that others will follow your lead. Family and friends will usually want to support you, and if you are able to focus on positive aspects of caring for your new baby, they will likely want to share in your joy! You should also consider offering friends and family members information about the developmental aspects of Down syndrome so that they, too, can share in celebrating your baby's accomplishments.

If someone does not react in the way you would hope, remember that he or she may have personal reasons for doing so that have nothing to do with you or your baby. People may be uncomfortable because they don't have accurate information about Down syndrome or have never met someone with the condition. It is possible that they may also be dealing with their own grief or pain. Grandparents, for example, may be dealing not only with the news that their grandchild has a disability, but also with the knowledge that their child is in pain. Just as new parents often go through the stages of grief, grandparents may also go through shock, denial and other emotions before they are able to accept the news. It is important to let them deal with their emotions at their own pace so they can also heal and begin to find joy in helping to raise their grandchild. Support group membership is usually open to grandparents and other relatives, so you might consider letting them know that it's an option available to them.

"Other relatives see my son as a person. They accept and encourage him in the same way that they would other family members."

Don't be afraid of sharing your emotions with your trusted friends and family members. They are often eager to provide emotional support or other assistance. If you share your feelings honestly and openly, you create opportunities for them to do so. Remember that whenever you do turn to others for assistance, it's a good idea to be specific about how much help you want or need, and what your needs are.

Additional Resources

BOOKS

Brothers and Sisters: A Special Part of Exceptional Families.

Gallagher, P., Powell, T. and Rhodes, C. (2006).
Baltimore, MD: Brookes Publishing.

This classic resource explores sibling relationships and methods to promote healthy, mutuality satisfying lifelong bonds.

Available from Brookes Publishing at
www.brookespublishing.com
or 800-638-3775

Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters.

Levine, S. and Skotko, B. (2009).
Bethesda, MD: Woodbine House.

Written exclusively for teenaged siblings of individuals with Down syndrome, this volume addresses siblings' most common questions and concerns in a simple q-and-a format.

Available from Woodbine House at
www.woodbinehouse.com
or 800-843-7323

Living with a Brother or Sister with Special Needs: A Book for Sibs.

Meyer, D. and Vadasy, P. (2000).
Seattle, WA: University of Washington Press.

Focusing on ways to confront siblings emotional needs, this book answers the toughest questions to ask. A publication of the Sibling Support Project.

Available from University
of Washington Press at
www.washington.edu/uwpress
or 800-537-5487

Married with Special-Needs Children: A Couples' Guide to Keeping Connected.

Marshak, L. and Prezant, F. (2007).
Bethesda, MD: Woodbine House.

This book examines ways couples deal with the unique problems that can arise from having a child with special needs.

Available from Woodbine House at
www.woodbinehouse.com
or 800-843-7323

Oh Brother! Growing up with a Special Needs Sibling.

Hale, N. (2004).
Washington, D.C.: Magination Press.

With humor and honesty, Becca shares her experiences and solutions she found to the challenges of living with Jonathan, her brother with special needs.

Available from Magination Press at
www.maginationpress.com
or 800-374-2721

We'll Paint the Octopus Red.

Stuve-Bodeen, S. (1998).
Bethesda, MD: Woodbine House.

A reassuring story for young children bewildered by Down syndrome and what it means for their relationship with their sibling, it concludes with a set of questions and answers about Down syndrome commonly asked by children.

Available from Woodbine House at
www.woodbinehouse.com
or 800-843-7323

Views from Our Shoes: Growing up with a Brother or Sister with Special Needs.

Ed. Meyer, D. (1997).
Bethesda, MD: Woodbine House.

In 40 essays, siblings ranging from 4 to 18 in age share observations and experiences they acquired growing up with a brother or sister with a disability.

Available from Woodbine House at
www.woodbinehouse.com
or 800-843-7323

ORGANIZATIONS

*National Dissemination Center
for Children with Disabilities*

Telephone: 800-695-0285
Website: www.nichcy.org

Also known as NICHCY, this organization serves the nation as a central source of information on disabilities in infants, toddlers, children, and youths. NICHCY offers the a wide range of publications dealing with finding support, including Accessing Parent Groups, Parent to Parent Support, Parent Training and Information Centers, Parenting a Child with Special Needs and, A Guide to Children's Literature and Disability and Children with Disabilities: Understanding Sibling Issues. Publications can be downloaded on the website or ordered by contacting NICHCY at the phone number above.

Sibling Support Project

Telephone: 206-297-6368
Email: donmeyer@siblingsupport.org
Website: www.siblingsupport.org

The Sibling Support Project, believes that disabilities, illness, and mental health issues affect the lives of all family members. It seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues.

The project's mission is accomplished by training local service providers on how to create community- based peer support programs for young siblings; hosting workshops, listservs, and website for both young and adult siblings and increasing parents' and providers' awareness of siblings' unique, life-long, and ever changing concerns through workshops, websites and written materials.



A Promising Future

Your child has been born, or is about to be delivered, into a world that offers more opportunities than ever before for people with Down syndrome to reach their full potential. Every day we expand our knowledge of how individuals with Down syndrome learn and the best ways to support their development. Scientific research is constantly yielding new information about the causes of Down syndrome and associated conditions. NDSS and many local and national advocacy organizations are working tirelessly to promote legislation that advances the rights of individuals with disabilities. All these efforts have opened up many doors for people with Down syndrome to pursue their dreams. This section discusses looking ahead to the future.

What does the future hold for people with Down syndrome?

There is still much progress to be made, but with the positive developments we've seen in recent years, you have every reason to be optimistic about your baby's future. For example, today the majority of children with Down syndrome are included in regular education classrooms alongside their peers. Research has shown that this inclusion has positive effects on the academic and social experiences of students with and without disabilities.

Many individuals with Down syndrome also graduate from high school and go on to college. The Individuals with Disabilities Education Act (IDEA) requires that teachers and school administrators work with you to create a plan for your child to ensure a successful transition to life after high school, and many new postsecondary programs for people with disabilities are available. In addition, we are seeing an increase in the amount of meaningful, satisfying employment opportunities available to people with Down syndrome and more options for independent living. Many people with Down syndrome are employed, live on their own, and some even get married.

The fact that these options are available today gives us reason to believe that for the next generation of people with Down syndrome – including your child – the future is even brighter.





How can I give my child the best chance at a promising future?

No one can tell you your child's potential, but there are many things you can do to give your child the best chance at a successful and happy life. First and foremost, your child will need lots of love, affection and support for healthy development. Like all kids, children with Down syndrome have their own unique talents and abilities, and it is important to recognize and celebrate those accomplishments. Your child will likely receive many early intervention services, including physical, speech and language, and occupational therapy. Still, instead of emphasizing what your child can't do, focus on what he or she can do!

This type of interaction is common with typically-developing children, and it should be no different for kids with disabilities.

Of course, babies and children with Down syndrome have certain developmental challenges that need special attention. In addition to providing your baby with varied experiences and constant opportunities for growing and learning, you'll also want to learn as much as you can about Down syndrome. There are many successful strategies for addressing specific challenges, but often, it's up to parents to track them down. Fortunately, many organizations and resources are available to you that can provide information on specific topics.

"The greatest words of encouragement that I have received and lived by in raising my son are: 'Do not let yourself be a barrier to him. You need to have the courage to allow him to try.' Whenever I'm afraid for him, I remember this."

Although your child with Down syndrome may need more attention from time to time, do your best to treat him or her the same as your other children and have similar expectations. It's important to remember that inclusion starts in the family. By living life and enjoying all the same activities that other families enjoy, you will be teaching your child that he or she has the same right as everyone else to live a full and active life. You will also be showing others that people with Down syndrome are more like the rest of us than they are different.

As a parent, you are a natural advocate for your child. You will probably come across many people who do not know very much about Down syndrome, and you'll be able to share information with them about your child's abilities and the potential of people born with this condition. As you become more comfortable in your role, you may find that you want to advocate for people with Down syndrome in more formal ways, and there are many opportunities to take your commitment to the next level!

Additional Resources

BOOKS

Believe in My Child with Special Needs! Helping Children Achieve Their Potential in School.

Falvey, M. (2005).

Baltimore, MD: Brookes Publishing.

This candid and reassuring guidebook for parents of children with special needs arms parents with optimism and inside knowledge the author traverses as both a parent and educator.

Available from Brookes Publishing at
www.brookespublishing.com
or 800-638-3775

ORGANIZATIONS

The Arc

www.thearc.org

The largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families

TransCen, Inc.

www.transcen.org

TransCen focuses on school-to-adult life transition and career development for people with disabilities.

Think College!

www.thinkcollege.net

Think College conducts research, provides training and technical assistance and disseminates information related to students with intellectual disabilities.

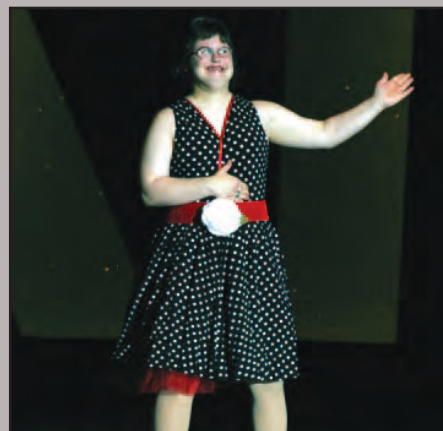
WEBSITES

Wrightslaw

www.wrightslaw.com

Wrightslaw provides accurate, up-to-date information about special education law and advocacy for children with disabilities.

The books, DVDs, organizations and websites listed throughout this guide are just a sample of the resources available for families of children with Down syndrome. Contact NDSS for further resources.





How NDSS Can Help

The National Down Syndrome Society (NDSS) has worked since 1979 to promote the value, acceptance and inclusion of people with Down syndrome. NDSS programming reflects our mission to enhance the quality of life for people with Down syndrome: Community Support Programs; the NDSS National Policy Center; Public Awareness Initiatives and the National Buddy Walk® Program.

NDSS Community Support Programs

NDSS is committed to providing the Down syndrome community with quality support and informational services.

- *NDSS leads a network of over 375 affiliate groups across the country, consisting of local parent support groups and other organizations that provide services to the Down syndrome community.*
- *Through our helpline and email service, NDSS responds to more than 8,000 requests for information on Down syndrome each year. The helpline is supported by a translation service that can be accessed in over 150 languages.*
- *Since 2005, the O'Neill Tabani Enrichment Fund has awarded more than 75 grants for post-secondary and enrichment courses to students with Down syndrome.*
- *A comprehensive, up-to-date resource for families and professionals, NDSS.org receives over 3 million page views each year and includes Spanish translation.*

NDSS National Policy Center

The NDSS National Policy Center in Washington, DC strives to protect the rights of and help remove barriers for all individuals with Down syndrome by working with Congress and federal agencies, and educating parents and self-advocates on how to advocate on the local, state and national levels.

- *The work of the NDSS National Policy Center is guided by a dynamic legislative agenda that includes a wide range of issues and touches every stage of life.*
- *The NDSS National Policy Center facilitates and mobilizes advocacy efforts for federal, state and local policies that positively impact people with Down syndrome across the country.*
- *The National Policy Center works with Congress and federal agencies to develop and improve legislation.*
- *Through the NDSS DS-Ambassador Program, the National Policy Center trains and educates parents, self-advocates and others in all 50 states.*
- *NDSS Government Affairs Committee (GAC) Program helps Down syndrome support organizations, parents and self-advocates across states to join forces with NDSS to achieve positive systems change at the state and local levels of government.*
- *The NDSS Buddy Walk® on Washington is an annual two-day advocacy conference that brings the Down syndrome community together to advocate at the national level.*
- *The National Policy Center organizes and participates in coalitions of national disability organizations.*

NDSS Public Awareness Initiatives

The purpose of public awareness at NDSS is to turn the mission of “value, acceptance and inclusion” into a comprehensive national public awareness message.

- NDSS proactively reaches out to national media outlets (including television, print, radio, online and social media) to secure editorial content on issues within the Down syndrome community, as well as promote positive and inspirational news stories.
- NDSS monitors all forms of media on a daily basis, 365 days a year, and responds to any inappropriate comments in an ongoing effort to educate and to promote accurate and positive messaging about Down syndrome.
- The My Great Story public awareness campaign seeks to ignite a new way of thinking about people with Down syndrome by sharing stories which are displayed in an online storybook on the NDSS website. The stories are written by people with Down syndrome, their family members, friends, coworkers, teachers and others.
- Public service announcements for the campaign in both print and digital forms have been featured in national and local media outlets across the country.
- The NDSS My Great Story Video Project features 10 short videos based on submitted stories to the My Great Story public awareness campaign.

National Buddy Walk® Program

NDSS established the Buddy Walk® Program to celebrate Down Syndrome Awareness Month in October and to promote acceptance and inclusion of people with Down syndrome in their own cities.

- The National Buddy Walk® Program is the world’s largest and most recognizable Down syndrome awareness program.
- Supported nationally by NDSS, the National Buddy Walk® Program is organized at the local level by parent support groups, schools, other organizations and individuals.
- Since 1995, the National Buddy Walk® Program has grown from 17 walks to more than 250 across the country and around the world.
- Each year, close to 300,000 people participate in a Buddy Walk® and nearly \$12 million is raised to benefit local programs and services and national advocacy initiatives to support all people with Down syndrome.
- The National Buddy Walk® public service announcement features the Emmy-award winning Imagination Movers, who, along with the number of self-advocates, encourage viewers across the country to find and participate in a Buddy Walk®.



With these and many other programs and services, NDSS is here for you and your family now and always!

Health care guidelines help define the standards of quality care for individuals with Down syndrome. In addition to specific recommendations for screening tests, they include information about the kinds of medical conditions that individuals with Down syndrome are at risk for and suggestions for early intervention, diet and exercise and other issues across the lifespan. We recommend that parents give these guidelines to their primary care physicians to ensure that their child's specific needs are addressed.

Down Syndrome Health Care Guidelines

(Based on "Health Supervision for Children with Down Syndrome" as published in Pediatrics)

Neonatal (Birth-1 Month)

- Review parental concerns. Chromosomal karyotype; genetic counseling, if not done prenatally.
- Check for signs and symptoms of gastrointestinal tract blockage (e.g., duodenal web, duodenal atresia, or Hirschsprung disease).
- Use typical growth charts from Centers for Disease Control (CDC), available at www.cdc.gov/growthcharts. Use weight/height assessment, as well.
- If constipation present, evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, or Hirschsprung disease.
- Radiographic swallowing assessment if marked low muscle tone, slow feeding, choking with feeds, recurrent or persistent respiratory symptoms, failure to thrive. Consider feeding referral, if needed.
- Echocardiogram read by a pediatric cardiologist and referral to pediatric cardiology if abnormalities present. Subacute bacterial endocarditis prophylaxis (SBE), in susceptible children with cardiac disease. If a heart condition is identified, monitor for signs and symptoms of congenital heart failure.
- Car seat evaluation to evaluate for apnea, low heart rate, or oxygen desaturation prior to discharge from the hospital at birth if child is hypotonic or has had cardiac surgery.
- Complete blood count (CBC) to rule out transient myeloproliferative disorder (TMD) or polycythemia.
- Review feeding history to ensure adequate caloric intake. Children with Down syndrome can usually nurse, and many can breastfeed successfully. Consider lactation consultation.
- Thyroid function tests – check on results of state-mandated screening at birth. Add TSH is the state-mandated screening only included T4 results.
- Newborn hearing screen – auditory brainstem response (ABR) or otoacoustic emission (OAE) – to assess for hearing loss.
- Discuss risk for respiratory infections.
- Discuss complementary and alternative therapies.
- Discuss cervical spine positions, especially for anesthesia or surgical or radiologic procedures.
- Review signs and symptoms of myopathy. If myopathic signs exists, obtain neck X-rays (C-spine).
- Eye exam for cataracts.
- Discuss value of Early Intervention (infant stimulation) and refer for enrollment in local program.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.

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Down Syndrome Health Care Guidelines

(Based on "Health Supervision for Children with Down Syndrome" as published in Pediatrics)

Infant (1-12 Months)

- Chromosomal karyotype; genetic counseling, if not already done.
- Discuss chances of having another child with Down syndrome.
- Use typical growth charts from Centers for Disease Control (CDC), available at www.cdc.gov/growthcharts. Use weight/height assessment, as well.
- Radiographic swallowing assessment if marked low muscle tone, slow feeding, choking with feeds, recurrent or persistent respiratory symptoms, failure to thrive. Consider feeding therapy referral, if needed.
- At 1 year of age begin to check hemoglobin count annually. Include (a) ferritin and CRP or (b) reticulocyte hemoglobin if there is a concern for a diet low in iron or if hemoglobin < 11g.
- Eye exam for cataracts. Ophthalmology referral to assess for strabismus, nystagmus and cataracts.
- Delayed or irregular dental eruption, hypodontia is common. First dental visit by 1 year.
- If constipation present, evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, or Hirschsprung disease.
- Discuss cervical spine positions, especially for anesthesia or surgical or radiologic procedures.
- Review signs and symptoms of myopathy. If myopathic signs exists, obtain neck X-rays (C-spine).
- Thyroid function tests at 6 and 12 months (FT4 and TSH).
- If a heart condition is identified, monitor for signs and symptoms of congenital heart failure, subacute bacterial endocarditis prophylaxis (SBE), as indicated.
- Well child care: immunizations including influenza.
- Newborn hearing screen follow-up and assessment by 3 months. Audiology evaluation at 6 months and every 6 months until "ear specific testing is accomplished and normal," at which point hearing screens can be done on an annual basis.
- Review signs and symptoms for obstructive sleep apnea.
- Discuss Early Intervention, including speech therapy, and refer for enrollment in local program, if not done already.
- Apply for Supplemental Security Income (SSI), depending on family income.
- Consider estate planning and custody arrangements; continue family support.
- Discuss complementary and alternative therapies.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.

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Down Syndrome Health Care Guidelines

(Based on "Health Supervision for Children with Down Syndrome" as published in *Pediatrics*)

Childhood (1-5 Years)

- Chromosomal karyotype; genetic counseling, if not already done.
- Discuss chances of having another child with Down syndrome, if not already done.
- If constipation present, evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, or Hirschsprung disease.
- Hemoglobin count annually. Include (a) ferritin and CRP or (b) reticulocyte hemoglobin if there is a concern for a diet low in iron or if hemoglobin < 11g.
- Thyroid function tests annually (FT4 and TSH).
- Review signs and symptoms of myopathy. If myopathic signs exist, obtain neck X-rays (C-spine). Contact physician if change in gait, change in the use of arms or hands, change in bladder function, neck pain, head tilt, torticollis, or new-onset weakness. (Note: Some athletic organizations might require a C-spine for entry and participation.)
- Trampoline use should be avoided in all children with or without Down syndrome under age 6 and only under professional supervision over age 6.
- Hearing exam every 6 months until normal bilateral ear-specific test. At that point, hearing exams should be done annually. Refer to Ears-Nose-Throat specialist for any abnormal hearing exam.
- Sleep study for everyone by the age of 4 regardless of presence or absence of symptoms. Review signs and symptoms for obstructive sleep apnea.
- Referral to pediatric ophthalmologist or ophthalmologist with expertise in Down syndrome annually.
- If a heart condition is identified, monitor for signs and symptoms of congenital heart failure, subacute bacterial endocarditis prophylaxis (SBE), as indicated.
- Use typical growth charts from Centers for Disease Control (CDC), available at www.cdc.gov/growthcharts. Use body-mass index (BMI) or weight/height measurements to assess weight proportionality. Consider referral to a dietician, especially for individuals who are "overweight" or "obese."
- Screen for celiac disease with IgA and TTG-IgA on an annual basis, if symptoms present and your child is on diet that contains gluten.
- Delayed or irregular dental eruption, hypodontia is common.
- Establish optimal dietary and physical exercise patterns.
- Encourage and model use of accurate terms for genitalia and other body parts any times these parts are discussed or examined. Remind person with Down syndrome that the only reason that anyone should be looking at or touching private body parts is for health (doctor office visits) or hygiene (bathing or showering).
- Well child care: immunizations; If chronic cardiac or pulmonary disease, give 23-valent pneumococcal vaccine age > 2 years.
- Review behavior and social progress, with particular attention to signs and symptoms of ADHD, autism, and other psychiatric/behavioral problems.
- Early Intervention: speech therapy, physical therapy, occupational therapy. Discuss complementary and alternative therapies.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.

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Down Syndrome Health Care Guidelines

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Adolescence (5-13 Years)

- Thyroid function test annually (FT4 and TSH). Hemoglobin count annually. Include (a) ferritin and CRP or (b) reticulocyte hemoglobin if there is a concern for a diet low in iron or if hemoglobin < 11g).
- Review signs and symptoms of myopathy. If myopathic signs exist, obtain neck X-rays (C-spine). Contact physician if change in gait, change in the use of arms or hands, change in bladder function, neck pain, head tilt, torticollis, or new-onset weakness. (Note: Athletic organizations might require a C-spine for entry and participation.)
- Trampoline use should be avoided in all children with or without Down syndrome under age 6 and only occur under professional supervision over age 6.
- Use typical growth charts from Centers for Disease Controls (CDC), available at www.cdc.gov/growthcharts. Use body-mass index (BMI) to assess weight proportionality.
- Low calorie, high fiber diet; regular exercise. Consider referral to a dietician, especially for individuals who are "overweight" or "obese."
- Auditory testing (annually).
- Monitor for obstructive airway; sleep apnea. Review signs and symptoms for obstructive sleep apnea.
- If a heart condition is identified, monitor for signs and symptoms of congenital heart failure. Subacute bacterial endocarditis prophylaxis (SBE), as indicated.
- Eye examination (every 2 years).
- Screen for celiac disease with IgA and TTG-IgA on an annual basis, if symptoms present.
- Review behavior and social progress.
- Discuss self-help skills, attention-deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), wandering off, transition to middle school.
- Discuss physical and psychosocial changes through puberty, need for gynecologic care in the pubescent female. Talk to adolescents and their families about the recurrence risk of Down syndrome if they were to become pregnant. Birth control and prevention of sexually transmitted diseases should be discussed with patients and their families. Sexuality education should be emphasized.
- Review dermatologic issues.
- Discuss complementary and alternative therapies.
- Continue speech therapy, physical therapy, occupational therapy, as needed.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.

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Down Syndrome Health Care Guidelines

(Based on "Health Supervision for Children with Down Syndrome" as published in Pediatrics)

Ages 13 – 21 Years

- Thyroid function test annually (FT4 and TSH).
- Auditory testing (annually).
- Review signs and symptoms of myopathy. If myopathic signs exist, obtain neck X-rays (C-spine). Contact physician if change in gait, change in the use of arms or hands, change in bladder function, neck pain, head tilt, torticollis, or new-onset weakness. (Note: Some athletic organizations might require a C-spine for entry and participation.)
- Hemoglobin count annually. Include (a) ferritin and CRP or (b) reticulocyte hemoglobin. (CHr if there is a concern for iron deficiency or if hemoglobin < 11g.)
- Review signs and symptoms for obstructive sleep apnea.
- Screen for celiac disease with IgA and TTG-IgA on an annual basis, if symptoms present.
- Review behavior and social progress.
- If a heart condition is identified, monitor for signs and symptoms of congenital heart failure. Subacute bacterial endocarditis prophylaxis (SBE), as indicated.
- Ophthalmologic exam, looking especially for keratoconus and cataracts (every 3 years).
- Low calorie, high-fiber diet. Regular exercise. Monitor for obesity. Consider referral to a dietician, especially for individuals who are "overweight" or "obese."
- Use typical growth charts from Centers for Disease Controls (CDC), available at www.cdc.gov/growthcharts. Use body-mass index (BMI) to assess weight proportionality.
- Continue speech and language therapy, as indicated.
- Facilitate transition: guardianship, financial planning, behavioral problems, school placement, vocational training, independence with hygiene and self-care, group homes, work settings.
- Discuss sexual development and behaviors, contraception, sexually transmitted diseases, recurrence risk for offspring.
- Discuss physical and psychosocial changes through puberty, need for gynecologic care in the pubescent female.
- Review signs and symptoms for obstructive sleep apnea.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.

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A Wealth of Information Online

Visit the NDSS website, www.ndss.org, to get answers to commonly asked questions about Down syndrome, read in-depth articles, learn about Down syndrome organizations and resources, and much more!



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