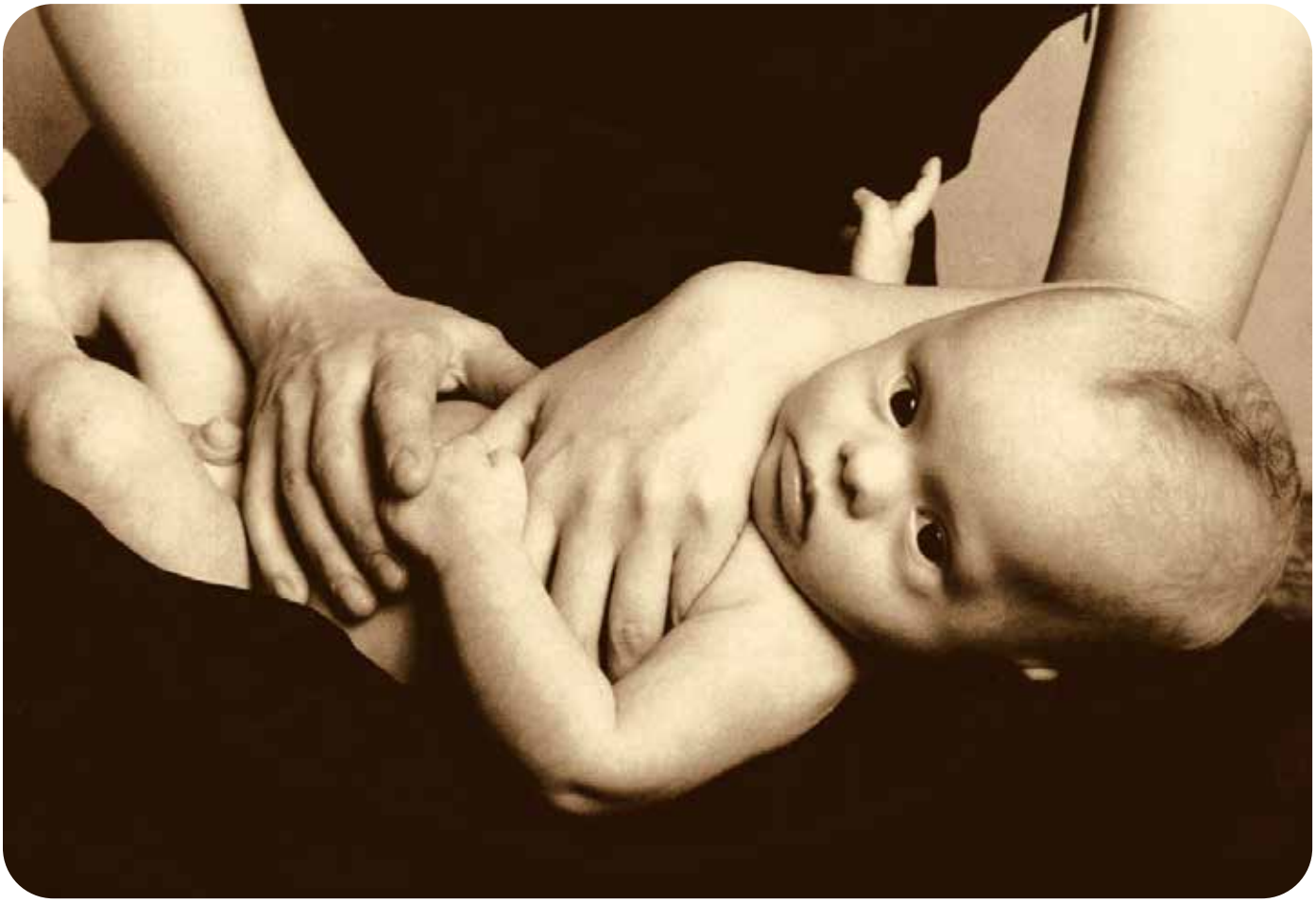
A Guide for New Parents
OF CHILDREN WITH DOWN SYNDROME

"This New Piece of My Heart"

Prepared and presented by the
Northwest Down Syndrome Association
www.nwdsa.org

"Let us put our minds together and see what life we can make for our children." Sitting Bull



Note: Throughout this book, we refer to babies and children as "he" or "she", depending on the original author's composition or to avoid confusion when referring to parent and baby in the same article. Whenever a gender-specific term is used for babies or children, it should be understood as referring to all genders. Similarly, referring to mother as "she" is for ease of comprehension and is not meant to imply that all mothers are female gender-identified.

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CONGRATULATIONS!

Congratulations on the birth, or upcoming birth of your baby! Whether this is your first child, or you already have children, becoming a parent is one of life's special moments—a fantastic opportunity and a unique challenge. The birth of a child prompts us to deeply consider the expectations we have for our new baby.

My wife Angela and I have two children, Quinn and Daniel, both young adults branching out into the world. As parents we have experienced challenges and joys. Daniel is our youngest and happens to have Down syndrome; having him in our lives added a new set of challenges and responsibilities for us as parents, but it's a life we wouldn't trade for anything.

Looking back on raising our family, it can sometimes be hard to remember the earliest days, but the truth is, there was a time when we were worried. We were ignorant and uninformed, and the hospital staff did not share any good news. As our journey unfolded, we built relationships with young people with DS and their families and educated ourselves. We have met the challenges we faced and learned how to thrive as a family.

One important thing we recognized early in the journey is that our son Daniel is 90% like every other kid. He has a fantastic, unique personality, a strong will, a sense of fun and adventure, and other social skills that make him a joy to be around. Yes, his speech is sometimes hard to understand, and he needs supports for learning, but he is a lifelong learner, but he has some real talents, and has amazed us with his art, dance, basketball, and computer skills.

Daniel graduated from high school in 2018. He is a comic book artist and enjoys traveling and exploring the world with his family. He loves to swim and snorkel in the ocean, do public speaking around disability rights and social justice, and enjoys just having fun like any other young adult. He has learned most anything he puts his mind to; through hard work and with the help of technology and a supportive community, he has access to things no one thought possible a generation ago. He attended classes at Portland State University and Portland Community College. For three years he held a summer job with Portland Parks and Recreation, and is working on starting his own business and finding his own place to live independently. Daniel continues to learn and grow every day, and it's a powerful thing to reflect on the things he has achieved. Over the last few years Daniel has become an online tutor and paid mentor to others, using his media and computer skills.

Often new parents wonder how their child with DS will affect their siblings. Our experience has been a positive one. Growing up, Quinn enjoyed having a brother who shared her interest in Legos, swimming, camping, and art. Today they enjoy music, computing, and attending concerts together. When they were younger, Quinn wrote, "I have 46 chromosomes; my brother has 47. Some people call this Down syndrome. I just call him my brother. I just call him Daniel." We can't imagine what our lives would be like without Daniel.

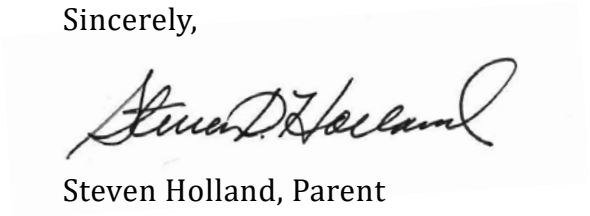
For Angela and me, and we hope for you too, the birth of a child is a miracle—a new creation. When our son Daniel was born on a cool, crisp April morning in 1999, I remember sitting in a chair in a large room next to the OB unit. Sunlight streamed through the windows and the whole room glowed with a golden hue. I sat there holding Daniel in my lap and feeling like we were in heaven.

Later I found out he had Down syndrome, and that day decompressed into a bad dream as I accompanied Daniel through the corridors of the hospital as he went through test after test. Late in the afternoon, as I walked out of the hospital with Quinn—who was 5 at the time—I had my head down and tears in my eyes. Quinn looked up and saw an amazing rainbow and said, "Hey Dad—look at that pretty rainbow!" At that moment, I had a surge in my heart and knew right then that Daniel was still a miracle!

As a parent, don't feel bad about taking time for yourself and your spouse (or significant other, or friend). Take time to enjoy the things that you like. When you have a child with Down syndrome, you can feel a big commitment to learn all you can and try to "fix things." This is all well and good, because these strong parental/caregiver urgings mean you care. But also take time to laugh and enjoy yourself, enjoy your children and your friends.

In closing, Dan wants to share a few of his thoughts: "I like my life, I love computers, art and music. You will have fun with your new baby. I help my mom and dad with a lot, and they help me too. I have big dreams and so can you."

Sincerely,



Steven Holland, Parent

AN INTRODUCTION TO DOWN SYNDROME

You may have recently had a test and your doctor or geneticist has told you that the baby you are expecting has Down syndrome. You may have recently given birth to a baby who has Down syndrome. Whatever your circumstances, you probably have many questions and concerns, as do your extended family, friends, and neighbors. We have been there and know the kinds of feelings and thoughts you are having, because we had them too.

Rest assured, you are not alone. There are other parents in your community, possibly right in your own neighborhood, who have a child with Down syndrome, and who would be grateful to talk with you and listen to your thoughts and concerns.

This guide is meant to help you in a similar way—to talk to you about things that are important for you to know as a parent of a child with Down syndrome. You may not be ready to talk with other people right now, and that is totally understandable. You may not even want to read or know anymore more right now about Down syndrome, so you can put this book away for later if you want. It's entirely up to you.

Above all—congratulations on your baby! We truly wish you all the best.

What is Down syndrome?

Down syndrome is a genetic (something you're born with) chromosomal anomaly that occurs in approximately 1 per 691 births in the United States. About 5,000 babies with Down syndrome are born in the United States every year. The national population of individuals with Down syndrome is estimated to be 400,000.

About 80% of babies with Down syndrome are born to mothers under the age of 35. About 1 in 350 babies born to mothers over 35 have Down syndrome.

Down syndrome is distinguished by the presence of an extra chromosome. Chromosomes are tiny particles that are present in every cell of our bodies. They carry the "blueprint" for all the characteristics we inherit from our parents. There are 23 pair of chromosomes in each cell—one of each pair comes from the father; one comes from the mother.

People with Down syndrome have an extra copy of chromosome 21. For some unexplained reason, an error in cell development results in 47 chromosomes rather than the usual 46. The extra chromosome slightly changes the development of the body and brain—these signs and characteristics are called a 'syndrome'.

The name 'Down' comes from the English doctor, John Langdon Down, who first described the syndrome in 1866. For better or worse, the name has been associated with this genetic condition. Hopefully the use of this name will change in the future—maybe you might be one of the people who help introduce this change!

People with Down syndrome generally have a certain degree of learning disability. This typically shows up in the young child as a delay in speech and learning. There may also be some degree of physical differences that may result in the child walking at a later age than his or her peers. The social skills of children with Down syndrome may or may not be delayed. The degree of disability varies

widely from person to person, and is more or less relevant given the context, and it is impossible to tell at birth what the degree of ability will be. It is true to say that all children are lifelong learners.

Children with Down syndrome are more like typically developing individuals than they are different. They look more like their families than they do one another, have a full complement of emotions and attitudes, are creative and imaginative in play and pranks, and grow up to live independent lives with varying degrees of support and accommodations needed. Down syndrome will not be the most interesting thing about your child as they grow up. Remember that raising any child fills your life with unimaginable delight and difficulties. There are no longer limits on how far our children will go.

What causes Down syndrome?

It is not known what causes the presence of the extra 21st chromosome. It can be either from the father or the mother. The most common type of Down syndrome, Trisomy 21 (also known as Primary Trisomy 21 or Regular Trisomy 21), occurs because of an unusual cell division before or at conception. The first cell of the developing baby has 47 chromosomes instead of 46, and all that baby's cells will have 47 chromosomes.

There is no way of predicting whether a person is more or less likely to have a baby with Down syndrome. There does tend to be a higher percentage of babies with Down syndrome born to older mothers, but we do not know why.

The three types of Down syndrome

Standard (Regular or Primary) Trisomy 21

About 95% of all people with Down syndrome fall into this group. This type of Down syndrome is the result of an unknown cause and can happen to anyone. In instances of Trisomy 21, the parents have normal chromosomes, but the baby has three rather than two chromosomes of the 21st pair.

Translocation

This type of Down syndrome occurs in about 4% of babies with Down syndrome. Part of the 21st chromosome becomes attached to another chromosome so that both parts of the large new chromosome move closer together as one. In about half of the people who have Translocation Down syndrome, the translocation is a one-off occurrence and does not mean that it will happen again in any future pregnancies.

In the other half, it occurs because one of the parents, though having a normal balanced chromosomal makeup, has one of the 21st chromosomes "stuck" onto another chromosome. In this case the chance of another child with Down syndrome being conceived is quite high. Parents can have blood tests carried out to find out more detailed information.

Mosaicism

This type of Down syndrome is also rare—only about 1% to 3% of people with Down syndrome fall into this category. In Mosaic Down syndrome the cells with the extra 21st chromosomes are mixed with other "typical" cells. In other words, only a certain percentage of the cells are affected.

Common questions

Could we have prevented our baby from having Down syndrome?

It is very important for you to know that you are not responsible for your baby's Down syndrome. Down syndrome is naturally occurring in all races, social classes, and countries throughout the world. It has occurred throughout history as far as we know. It can and does happen to anyone.

If we have another child will they have Down syndrome?

Trisomy 21 is not hereditary. However, once you have had one baby with Down syndrome, your chance of having another child with the condition is increased. Overall this chance is between 1 in 100 and 1 in 200, which is considerably less than the chance of having twins 'out of the blue.' When thinking about your next pregnancy, you might consider talking to a genetic counselor who could talk things through with you in some detail.

How will the extra chromosome affect our baby's life?

All people with Down syndrome share certain physical characteristics, though not every child with the condition has every characteristic. Your baby will have inherited physical characteristics from both parents, just like any other child. They will also have some of the common signs of Down syndrome. Remember, your baby is unique, and unlike any child ever born before. Some parents wonder if the degree of physical characteristics associated with Down syndrome present in their child will somehow predict how they will develop. In fact, there is no way to know at this early stage just how your child will develop.

The extra chromosome means that your baby will take longer to reach certain milestones and will have a certain degree of learning difficulty, but most children with Down syndrome learn to walk, talk, ride a bike, read and write, and in fact do the things that other children do—it's just that their development is delayed to some extent.

Many of us have misconceptions about terms like "developmentally delayed". The proper term is "intellectual disability". We may have had limited or no contact with people with Down syndrome in the community and may not realize that there is a wide variation in mental abilities, behavior, and physical development in individuals with Down syndrome. On standard IQ tests, those with Down syndrome most often score in the mild to moderate range of intellectual disability.

The high rate of learning disabilities in students with Down syndrome sometimes masks a range of other abilities and talents. Each individual has their own unique personality, capabilities, and talents. As they grow into adults, some people with Down syndrome play competitive sports, perform in theater and dance groups, become artists, graduate from high school, attend college, have relationships, get married, hold jobs, live independently, and make significant contributions to their communities every day.

What are the common signs of Down syndrome?

Your baby may have looser muscles and joints than other babies. This will improve as your baby gets older. Your baby may have a lower than average birth weight and put on weight at a slower pace than other babies, and generally will be of smaller stature than their peers. Down syn-

drome-specific weight and height charts are available at growthcharts.com or ndsccenter.org.

Babies with Down syndrome often have beautiful, almond-shaped eyes that slant slightly upward and outward, and sometimes have striking Brushfield spots—small white or grayish/brown spots—on the periphery of the iris. Their eyelids may have an extra fold of skin (epicanthic fold), which appears to exaggerate the slant. This does not mean there is anything wrong with their eyes. They just have their own unique look.

Many babies with Down syndrome have a single palmar crease, which runs right across the palm of the hand. Doctors often look for this characteristic crease as a sign that a baby may have Down syndrome. Some babies with Down syndrome may not have the crease, and babies that do not have Down syndrome may have the crease. Your doctor or geneticist will be able to tell you for sure once appropriate tests are completed.

One thing is for sure—all babies are different from each other and the same is true of babies that have Down syndrome. This means that in some babies the characteristic signs of Down syndrome are fairly easy to recognize soon after birth, while in some babies they are not. However, experienced doctors and midwives are usually very good at picking up subtle differences, which suggest that a blood test should be done to check the chromosomes.

"The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart." Helen Keller

Down syndrome myths and truths

MYTH: Down syndrome is a rare disorder.

TRUTH: Down syndrome is the most commonly occurring genetic condition.

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

TRUTH: Life expectancy for individuals with Down syndrome has increased dramatically in recent years, with access to good medical care and education about diet and nutrition. People with Down syndrome can thrive well into their 60s and beyond when granted the opportunities they need to develop life skills and independence.

MYTH: Down syndrome is hereditary and runs in families.

TRUTH: Down syndrome is hereditary in approximately 1% of all instances. In the other 99% of cases Down syndrome is completely random and the only known factor that increases the risk is the age of the mother (over 35). Translocation is the only type of Down syndrome known to have hereditary link. Translocation accounts for 3 to 4% of all cases of Down syndrome. Of those, one third (or 1% of all cases of Down syndrome) are hereditary.

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

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

MYTH: People with Down syndrome have severe cognitive delays.

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

MYTH: Most people with Down syndrome are institutionalized.

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

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

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

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

TRUTH: Children with Down syndrome are included in regular academic classrooms in schools across the country. In some instances, they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. Best practice in education is for full inclusion in the social and educational life of the community. Individuals with

Down syndrome graduate from high school, participate in postsecondary academic and college experiences, and receive college certificates and degrees.

MYTH: Adults with Down syndrome are unemployable.

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

MYTH: People with Down syndrome are always happy.

TRUTH: People with Down syndrome experience the full range of emotions. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.

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

TRUTH: People with Down syndrome socialize and have meaningful friendships. Some choose to date, form ongoing relationships, and marry.

MYTH: It's OK to use the "r word" if you don't really mean it.

TRUTH: It is never acceptable to use the word "retarded" in any derogatory context. Using this word is hurtful and suggests that people with disabilities are not competent.

Taken in part from the National Down Syndrome Society website, (800) 2214602, ndss.org

My college life

By Rachel Esteve

I am 24 years old. I go to college. The program I am in is called Think College Inclusion Oregon. I had to do an application and essay about my life. They looked at it and they thought I was a great fit. I was so happy about it.

All my classmates are awesome. Very nice to me. I am learning a lot. My major is Works of Art. Every term there is an event with my peers and staff called Seminars. We discuss what we have been doing in our classrooms. We also go over how to communicate with our teachers and peers and mentors and staff.

College has been a great experience for me. I love everything about it.

[Update: Rachel is now a college graduate and working her dream job in childcare. She continues to be a role model for youths in the community.]

You're a hero to somebody – clown shoes optional

By Paul Carson

If you're a new father, congratulations. You just landed the best job in the world! Fathers are looked at as heroes, as protectors, as clowns and sometimes as jungle-gyms. Fathers are endlessly comparing their children's accomplishments—and being guys, sometimes doing so competitively. It may be hard for us to hear these comparisons, particularly if our kids are behind on a milestone or struggling to learn a skill. It may sting to hear about your friend's son taking his first steps when your boy or girl isn't quite there yet.

At age two-and-a-half, our son Anthony is still working on his first words. He points enthusiastically and sometimes yells because he doesn't have a vocabulary yet. We go to speech therapy and work with just about every speech-learning tool there is. But what I like to focus on is how much Anthony understands. His speech may be delayed, but he listens and understands a lot. We've learned never to underestimate what words he may have picked up.

Anthony still needs help walking independently. He's got orthotics and has had all kinds of therapies, but he still needs help from us to balance and go any kind of distance. But he loves walking! While he still needs a copilot, he loves trying and we can tell he's got the heart of an explorer.

He loves to climb and has a reserve of energy I truly envy.

The point is, dads, for every delay and struggle, if you look for it, you will find an amazing strength and ability in return.

Our children are astonishing! They may take some time getting there, but we should never diminish their potential. Our children look to us to see what's possible. As dads, we must remember that every child is different and it's our job to help our kids believe they're capable of anything. That's what sons and daughters look to their fathers for— and that goes beyond any diagnosis. That's universal for anyone who's lucky enough to be a dad. So take heart—our kids may need some extra help sometimes. How wonderful that when they look for it, we're there to let them know that that's okay—and that's an amazing feeling.

An unexpected gift [excerpt]

By Abby Braithwaite

The tears flowed freely that night as we were left alone with a fridge full of food, flowers wilting in their vases and the weight of our fears falling over us again.

We were afraid of the medical side of Down syndrome—the difficulties that Adara might encounter on her path through life. We were afraid our lives were going to be overrun with therapists and experts telling us all the things we had to do to fix our child. And, mostly, we were afraid of our own ignorance of the task at hand. We had been planning to parent by instinct. But how could our instincts ever guide us through this situation? We felt alone and lost, and very much in love with this tiny creature who needed us so much.

The need to keep Adara fed and growing carried us through those first few weeks—each feeding required David and me to sit forehead to forehead on the bed, Adara at my breast with David supplementing with a syringe as she learned to suck. This method, though time-consuming, provided our family with a level of intimacy that I wouldn't trade for anything.

We had several appointments with the pediatrician and lactation team. With each visit we relaxed a bit more, reassured that our instincts could inform us. Maybe it wasn't going to be all that different from parenting any other child.

That is not to say that we were done grieving. But as the days passed, the waves of sadness were farther apart and less wrenching as we settled into a routine.

Today Adara is a happy, healthy child. She loves swimming with her dad and

playing with the dog. She likes to wrestle and giggle and can play a rollicking game of peekaboo. She loves to sit quietly and listen to a good book. She is engaging and talkative, and without question the cutest baby I know. In short, she is doing all the things a baby does.

We have a long journey ahead of us, and I am sure there will be difficult times. But I also know that we have the strength to get through this with dignity, and I am confident that we'll find plenty of opportunities for fun along the way.

I have long said I am one of the luckiest people I know. Life is a wild journey; our job is to make the most of it.

[Update: Adara is now a teenager heading to high school. She loves Hamilton and American Ninja Warrior equally and is always on the lookout for the best local barbecue.]

YOU, YOUR NEW BABY, AND YOUR FAMILY

What you may be feeling

When parents are expecting a new baby, most have many hopes and dreams for their child. When a child is born with Down syndrome these dreams feel broken—parents become shocked and confused. Most parents only have a vague idea of what Down syndrome is, but a great deal of anxiety about what it might mean.

Whether you had a prenatal diagnosis or learned about Down syndrome after your child was born, this can be very difficult news to process. Parents are not at their strongest, physically or emotionally, at this time, and many have strong feelings that can be disturbing.

Shock, panic, despair, disbelief, hopelessness, guilt, shame, rejection, and pain—a pain so deep and searing that parents sometimes have difficulty describing it—are common reactions when parents find out their child has Down syndrome. We are afraid that we will not be able to handle the situation. There are so many questions and so much uncertainty about the future. We wonder if we will be able to manage this overwhelming responsibility the rest of our lives, or if there is light at the end of the tunnel.

Grief

Grief for the loss of the expected child is a common feeling among some new parents. People go through the grieving process at different speeds. Many will revisit the process over and over again. The process consists of (in no particular order): Denial, Anger, Bargaining, Depression, and Acceptance. Each stage lasts varying amounts of time. What u will also come to experience is joy—even though you may not feel this initially it will come. Experienced parents can tell you this is true!

Sorrow

When you are told your baby has Down syndrome, it would be very unusual for you not to feel sad and confused. If you can let this feeling out, for example by having a good cry, you will likely feel better and find it easier to cope with things. Crying is natural—it is your body's way of releasing tension and emotion without harming yourself or others.

Anger

Most parents ask, "Why did this have to happen to us?" There really is no answer to this question, although it is perfectly reasonable to think this way. Many parents feel angry at the world, or even God, for letting this happen. You may have had experiences with doctors, nurses, and other medical and hospital staff that was not positive or supportive. This too can lead to anger. If you can talk it through with people you care about, like a spouse, family member or friends, this may be very helpful.

Guilt

Some parents may feel guilty. This too is a natural reaction. You must recognize that nothing you have done caused the Down syndrome—it has a complex genetic basis that we are just beginning to understand.

Shock

You may feel 'numb' and detached from things around you. This is normal—this is your mind's way of protecting you from more pain than you can deal with. As the shock subsides, other common reactions include:

- Being forgetful
- Having difficulty concentrating on things
- Feeling as though you are in a bad dream
- Denial

Family dynamics

Parenting is both a rewarding and challenging task for most parents. Being the parent of a child with a disability adds more challenges and possibly more rewards as parents celebrate achievements that are taken for granted for typically-developing children.

Take time to get to know your baby as part of the family. Your baby will have his or her own personality and characteristics just like any other child. It is important to remember that your baby with Down syndrome shares many more similarities than differences with other children without Down syndrome.

Research shows that the majority of families with children with Down syndrome lead ordinary lives. This does not mean that families do not have additional demands and challenges to cope with—it means that most families find the resources to meet the additional needs of their children.

There is little reason to think that the new baby will have a negative effect on their sibling's lives if positive relationships are encouraged. Brothers and sisters will usually be lifetime friends, advocates, and supporters of their sibling with Down syndrome.

Research shows that most children get along well with their sibling with Down syndrome and are able to enjoy their own hobbies and pursuits within the family dynamic. Most siblings are not embarrassed by their friends meeting their brother or sister with Down syndrome. Many parents have felt that their other children became more compassionate and empathic toward people with all kinds of disabilities as a result of having a sibling with Down syndrome.

Your baby with Down syndrome may present your family with many challenges just like any baby, but will also give your family much pleasure and joy.

Will having a baby with Down syndrome disrupt our marriage?

Research shows that no more marital difficulties are experienced by parents of children with Down syndrome than by the rest of the population. In fact, when asked about the effect of having a child with Down syndrome in the family, parents often say it has brought them closer together. It may be that parents find strengths within themselves they did not know they had, and that they derive some satisfaction from knowing they are capable of caring for a child with specific needs.

What should we say to friends and family?

Well-meaning friends and family often fail to understand the great potential that children born with Down syndrome have and the joy they bring to their families. Upon hearing the news that your new baby has Down syndrome, they may not know what to say. Consequently, they may resort to clichés or sentiments of pity. Some people may even avoid contact, because they simply don't know how to approach you. Most friends and family will take the first cue from you. Many parents handle this by creating a joyful birth announcement that includes the diagnosis of Down syndrome as additional information—just as one would the length, weight, or time of birth. As your child grows and develops, caring family members and friends will look upon them more and more as your child and as a person, rather than as a diagnosis or stereotype.

Telling Siblings

Children take their cue from their parents. If you feel positive about the new baby, they will too. It is important to explain to them as soon as possible that the new baby may learn more slowly. Let them know that the baby will take more time and will need extra care and attention, but their new sibling will be able to do most, if not all, of the same things every other baby does. The new baby is a member of the family first, and just happens to have Down syndrome.

You may feel under pressure to do things with your baby to help them with their development more than you would have with other children. Try to integrate your baby into the family routine as quickly as possible. It is important not to restrict the rest of the family's activities more than necessary because the baby has Down syndrome. Take the baby out and about with the family—this will help older siblings come to terms with the condition and will give the baby plenty of new experiences and stimulation, and the baby will be happier as well!

Telling the Grandparents

Grandparents will undoubtedly go through the same feelings as you, but without being able to fill their time with the practical tasks of looking after the baby. Where possible, try to include them in doing things with and for your baby and allow them to get to know your baby— for example by holding, talking to and watching your new baby.

Telling Friends and Acquaintances

Tell others as soon as you can. People can unwittingly say thoughtless and hurtful things out of embarrassment and ableism. They have pictured you with your 'normal' new baby and may have difficulty knowing how to reach out now that the baby is born with Down syndrome. If you can be positive about your baby, friends will follow suit.

Getting support

Having someone who can listen and understand is extremely important for new parents. Often, merely seeing another parent of a child with Down syndrome who looks "okay" is living proof that one can survive such an unexpected situation. An experienced or veteran parent can be more sensitive to the feelings involved and offer appropriate support. They can also tell you that you will learn to not only survive but thrive!

In the Resources section of this book, you'll find additional information about other local and national organizations, Early Intervention contacts, and a list of recommended books and websites. You can also visit our website at nwdsa.org for more resources and links specific to Down syndrome, and abicommunity.org for resources relating to inclusion for children and adults with any disability.

The future for your child with Down syndrome

Your child will have more opportunities than a child born with Down syndrome ten years ago. As young people with Down syndrome show what they can do with access and the support of their communities, and as they fully participate in regular programs, expectations raise and more doors open for others.

More and more, we see the diversity of our families represented on television, in print, and at the movie theater. Actors, writers, musicians, artists, models, athletes, and entrepreneurs with Down syndrome inspire others to appreciate the contributions and humanity of those with disabilities.

Just as importantly, thousands of people with Down syndrome across the country are quietly going on with their lives without fame or fanfare and transforming their communities by just being present and being themselves.

In the past, people with Down syndrome were not treated with the respect they deserved and were often segregated from the general population and denied opportunities of education and independence. Today, they learn in regular classrooms with children who will one day be their coworkers and neighbors. They have dreams and determination to reach their goals of higher education, careers, housing, and relationships.

What kind of financial provision can we make for our child's future?

Parents, grandparents, relatives and friends can provide financially for their child with Down syndrome by establishing a trust. The trust can be setup and administered by banks, insurance companies, and the local Arc. The trust can be funded by periodic contributions (savings), by life insurance policies and wills.

The Stephen Beck Jr., Achieving a Better Life Experience Act of 2014 (ABLE Act) established the creation of ABLE accounts for individuals with disabilities. Oregon and Washington ABLE Savings Plans provide tax-advantaged savings accounts for individuals and their families to save for qualified disability expenses without losing federal and state benefits. Learn more about the financial empowerment tools available at abicommunity.org under **resources > financial**.

A final consideration

Allow your family, friends and neighbors some time to learn about Down syndrome, reminding them if necessary that Ds is just a small part of who your child is and will become. Staying included in your mainstream community is important to your child's development and your peace of mind.

Try to get some rest. You are allowed to feel however you feel, and so are others who love you and your baby. Childbirth is hard work; many of your emotions stem from a new life coming into your family. You deserve congratulations and wonderful gifts. Have the good cooks among your family and friends bring over their best meals. Take time to welcome and enjoy your baby. They grow up fast.

Visibility! Role models with Down syndrome take the spotlight

Individuals with Down syndrome can be found in more visible roles in popular media than ever before. From TV to comic books to catalogs, the faces of Down syndrome are becoming increasingly common in the media.

Seeing role models who "look like me" expressing disability pride in mainstream culture helps others see their own potential and their importance in the community.

Actress Lauren Potter portrayed Becky on the Fox hit Glee *and went on to become a White House advisor.*

Luke Zimmerman plays Tom on The Secret Life of an American Teenager.

The show Ozark *has a Character named Tuck played by Evan George Vaurazeris.*

Born This Way *was an award-winning reality series featuring young adults with Down syndrome pursuing dreams, forging relationships, and defying expectations.*

Actor Zack Gottsagen received critical acclaim for his breakout performance in the 2019 film The Peanut Butter Falcon.

*Other notable actors with Down syndrome include Jamie Brewer (*American Horror Story*), Chris Burke (*Life Goes On*), Pablo Pineda (*Yo, también*), Sarah Gordy (*The A Word, Call the Midwife*) and so many more!*

The comic book Superb *features the first ever superhero with Down syndrome. The series* Stumptown *also features a character with Down syndrome.*

Concepts of beauty are evolving in the

mainstream which means increased diversity in fashion and modeling.

In 2018, Lucas Warren became the first Gerber "spokesbaby" with Down syndrome.

A young model named Ryan Langston appears in ads for Target and Nordstrom.

Madeline Stuart is an Australian fashion model who struts the catwalk in New York, Paris, and London.

Sujeet Desai is the first musician with Down syndrome to play at Carnegie Hall. He has mastered seven instruments and performed in 13 countries.

Pablo Pineda is an educator, known for being the first European with Down syndrome to obtain a university degree.

Chelsea Werner is a gymnast and model. She was unable to walk until she was nearly 2 years-old, and went on to become a US National Champion in gymnastics at the Special Olympics.

CARE OF CHILDREN WITH DOWN SYNDROME

Babies and children with Down syndrome often undergo extensive health evaluations, infant stimulation, physical therapy, communication enhancement, developmental evaluations, and other professional interventions. Throughout this process, it's important to keep in mind that every child deserves to be surrounded by people who love, respect and admire all children. The everyday things that parents, siblings and friends do with your child are all very crucial to healthy development and will help your child live a natural life

Children with Down syndrome benefit from the same love, care, attention, and inclusion in community life that help every child grow. Studies show that all children thrive in a loving and caring environment.

Suggested activities to do with your baby

Spending time with your baby is a joyful experience. If they have Down syndrome, it is helpful to do a little extra to make sure your baby gets the stimulation and interaction they need to develop to the best of their ability.

Blow at all parts of your baby's body. Tickle, rub, pat and prod them. Roll them around in a safe manner. Do not always have your baby dressed. Place the baby naked onto a scratchy woolen blanket or a crackly paper so that the nerves of the body experience something quite different than the dull rubbing of clothing. The noise of the paper will also be an incentive for the baby to move—sounds are the baby's reward for moving.

Forget about the baby's comfort now and then. Put them near the end of the crib, with their feet against the railing as they will likely push against it. Place the baby on his tummy and hold some bright, noisy object in front of their eyes, but above the head. This will encourage them to lift the head and exercise the neck muscles. Whistle and sigh if it makes the baby stretch or arch their back. Use odd sounds, which suddenly lapse into peaceful silence. Do not be afraid to be child-like with your baby. It is surprising how 'aahs' and 'oohs' can provide wiggles and happy twisting that no serious talk can ever achieve.

Place bells on or near the feet. This will make the baby kick more frequently and more purposefully. If the bells are placed on each side, he will even learn to use alternative limbs. Carry the baby around in a baby sling. In this way they get rocked, lowered, lifted and turned without much effort on your part. This stimulates the sense of balance while they feel loved and a part of your routine.

Tease the baby into turning, stretching or bending movements by holding a desired object at a slight distance. It may be good for an inactive baby to learn that effort has its reward.

If the baby does not attempt to crawl, give her the joy of a bath in which you lie her down on her tummy over a large rolled up towel. This comfortable bulge should support the chest and abdomen while leaving the limbs to dangle freely in the water. When splashing in this position, the baby may come very close to the mechanics of crawling.

It is helpful to get down to their level with them at times. For the baby the task at hand is gigantic. Why must we then make it harder still by standing over them like a giant?

If the baby is still building leg and knee strength, you can sit opposite your baby on the floor, with the soles of your feet touching her feet, and push against each other. You can be the wall on which the baby gradually raises herself from crawling to a standing position. You could also make a ramp with your legs on which she can learn to climb.

Last but not least, make your child itch with curiosity. Do something secretive nearby, or clatter about unseen so that the child will want to overcome the physical stumbling block and crawl over or get up to see you.

Medical and healthcare needs

Babies born with Down syndrome can be just as healthy as other babies, although quite often they are born with some specific medical needs. Some of these medical needs can be serious. In the past, medical and health needs of individuals with Down syndrome were not adequately addressed, and health statistics did not paint a very good picture. However, with the leaps in technology and improvements of treatments and procedures of recent years, the average life span has increased to 60 years. Babies with Down syndrome grow up to lead healthy, active lifestyles. Insurance covers most necessary surgeries and treatments.

For the most updated healthcare information, please visit: ndsccenter.org/programs-resources/health-care/

We encourage you to share this information with your infant's medical provider. We also have a *Healing Hearts* booklet available for families of new babies who require heart surgery; you can find it at nwdsa.org.

"How lovely to think that no one need wait a moment. We can start now, start slowly changing the world."
-Anne Frank

A birth story [excerpt]

By Leah Thompson–corabean.com

When my newborn girl Cora was placed on my belly, she looked at me with her big blue eyes and blinked. And I just knew that something wasn't quite as we expected. Afraid even to think it, my first thought was, "She looks like she has Down syndrome." But I thought that I had to be wrong.

Our Midwife came to us and told us what I will remember for the rest of my life. She said that Cora displayed several physical characteristics of a chromosomal abnormality. She explained what those characteristics were and told us that a blood sample would tell us for sure. I was lying there, holding my sweet girl and thinking that there was no way it could be possible.

But it didn't take long to be thankful for our girl. She is so easy to love. So sweet, so beautiful, so incredible. We really can't imagine her any other way. Down syndrome indeed doesn't seem so bad.

Cora is going to have open heart surgery in the very near future. In the meantime, we deal with her Down syndrome every day. I read, talk to other parents of babies with Ds, plan for her therapy appointments, and talk with friends and family.

Our little Bean is only 9 weeks old, but already I can't imagine how I ever existed without her. It's like I spent my whole life waiting only for her. That she is the part of me that has always been missing. I know that she will bring challenges. But what I unequivocally know in every bone in my body and with every breath I take, is that she is my baby, my girl, that she was born to be with me, and that I have never loved anything so very much. And I am so thankful for her. I am thankful, even, for Down syndrome. Thankful for all that my girl is, and all that she brings to the world. My beautiful little girl. I love her so very much.

[Update: Cora fully recovered from her successful heart surgery. She is now school-age and a proud big sister. You can read about Cora and her family's experience with heart surgery in our book Healing Hearts, *a free resource for families of children with Down syndrome facing heart surgery, available at nwdsa.org.]*

The perfect daughter

By Michael T. Bailey

Excerpted from *You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities*, © 2001 Citadel Press/Kesington Publishing Corp.

On April 2, 1988, at seven o'clock in the morning, a doctor handed me the swaddled, red, and wrinkled bundle that was Eleanor Sumner Bailey. Only my wife, Jonna, heard him say the ominous words: "Get a pediatrician."

"Your daughter has an extra chromosome..." I remember my first thought: "Oh! An extra chromosome. Smart kid. Chip off the old block." An extra anything seemed like a real advantage in this world.

"Your daughter has an extra chromosome," the masked pediatrician continued, "It's called Down syndrome. If you're interested, we have some literature you can read before you leave the hospital."

He abruptly turned and left the room. Two nurses began to sob. I looked at Jonna. She looked at me. Thus began our wrenching, happy, challenging, humanizing, angry, crusading, broadening, rejoicing, proud adventure in parenting a child with a developmental disability.

As for so many other families of children with disabilities, our first experience was in a "medical" environment. It took us a while to realize that "medical" environments thinks about children with disabilities using a "medical" model—a model that teaches parents to think of their child as sick. Subtle and not-so-subtle messages tell parents to do everything they can to make their child more "normal."

Eleanor was not sick. She did not need to be made well. She was not broken. She did not need to be fixed. What she needed was a family that recognized that girls with Down syndrome are short. There was nothing wrong with her.

Gradually, it became clear that I needed to view Eleanor's life not from my own experiences and expectations but from hers. The question should not have been: "How can I make her taller?" The question should have been: "What can I do to help the world accept her for the person she is?"

Each of us needs to believe sincerely that our children are people, first and foremost, and valued members of the community. Inclusion begins at home.

The world will not respect your child if you do not. Set an example by proudly taking your child wherever it is appropriate for children to go.

Believe in your heart that you are the world's leading expert on your family and your child. Let nothing change that belief.

Parenting a "special needs child" inevitably means dealing with experts. Doctors, therapists, educators, government officials, members of the clergy, neighbors, relatives, and the postman may all feel the need to give you advice. Much of this information will be useful. But never let "experts" take your place. You need to have your own dream for the best possible life for your child. Do not let anyone turn you away from it.

Eleanor has a great life, and we believe it will only get better. We are working to see that Eleanor will have the opportunity to direct her own services when she becomes an adult. We believe that Eleanor should have the right to make her own decisions as she grows—even a few bad ones.

She has the right to privacy and when she is an adult, she will have the right to intimate relationships. She has the right to dream her own dreams and live her own life. She has the inner strength of a queen and the compassion of a social visionary.

In more ways than we imagined, Eleanor is the daughter we dreamed about. She cares more for other people than anyone I have ever known. She has a great deal to offer the world and will make her own contributions to her country, her community, and her family.

She is the perfect daughter we expected.

[Update: Eleanor Bailey is in her thirties. She is an activist and role model and enjoys a life surrounded by family and friends. She has spoken at events all over the country and is passionate about equity for all. Lately, she's gotten into making art and posting as "Cats and Coloring" on Instagram.]

FEEDING YOUR BABY WITH DOWN SYNDROME

This section of the guide will provide information on feeding and nutrition of your baby and toddler. There is a lot of information here, and we invite you to read it as it becomes relevant.

As with other areas of development, every baby is different, and there may be some tips that are more relevant to you than others. The idea of introducing solid food may feel far away right now, so feel free to come back to it in a few months.

Breastfeeding

Babies with Down syndrome can often breastfeed successfully, although historically, many mothers have not been given the information needed to support breastfeeding a child with Down syndrome.

This section is intended to provide you with some tips to try at home, as well as give you the tools to advocate with your child's lactation team and pediatrician if you and baby need some support.

We know that babies benefit from breastfeeding or receiving breast milk. Sometimes information and encouragement is all that is needed to get over the challenge; sometimes practical interventions are required; and other times, breastfeeding just doesn't work out. Insurance often covers supplemental nursing devices and pumps. Your team can provide information on other feeding options.

Remember—your baby thrives on your love as well as any nourishment that you give him. The most important thing is that your baby receives the best nutrition available, whether that's from mother's breast, a bottle, or a feeding tube.

Benefits of breastfeeding

- Human milk will boost your baby's immune system and protect against numerous auto-immune disorders such as celiac disease, asthma, and allergies. This is especially important for babies with Down syndrome, since they are prone to respiratory and viral infections.
- The repetitive sucking action during breastfeeding will strengthen your baby's lips, tongue, and face. This serves as a stepping stone for future speech development.
- Breastfeeding is convenient! It is always available and contains all of the nutrients, calories, and fluids your baby needs.
- Hormones produced during breastfeeding help your uterus to shrink back to the size it was before pregnancy.
- Breastfeeding has been shown to reduce the risk of developing ovarian cancer and breast cancer.
- Breastfeeding provides warmth and closeness. The physical contact helps create a special bond between you and your baby.

Breastfeeding Your Baby

The early days of breastfeeding are a time for you and your baby to get to know each other and learn to breastfeed effectively. Every nursing couple must make some adjustments during this time because every baby is unique. As you get acquainted with your baby, you will discover that babies with Down syndrome have physical characteristics that may have an impact on breastfeeding. While you probably will not encounter all of the challenges discussed here, understanding your baby's particular needs will help you to get breastfeeding off to a good start.

> "Breastfeeding helped with my bonding to James initially when my world was turned upside down by his arrival."

Positioning

Positioning your baby in a comfortable and supportive arrangement will preserve her energy and allow her to use this energy for feeding. Proper positioning will also help your baby get more milk for her efforts and better stimulate your milk supply.

- Use pillows as needed to support your baby's body so her mouth is level with or slightly below your nipple.
- Always hold your baby very close into your body for comfort and the best latch.
- If your muscles feel strained, use pillows to help support your back, shoulders and arms. When your baby is tucked right in against your body, your arms aren't working so hard. Remember to relax! Your milk will flow best when you are calm and comfortable.

Latching on

- Expressing some milk onto your nipple prior to breastfeeding may encourage your baby to latch on.
- Ensure your baby gets a large mouthful of breast tissue. This will help your baby draw the milk out and stimulate the breasts to produce more.
    - To do so, hold her in a comfortable position, using your free hand to support your breast in the C-hold—thumb on top, fingers underneath—well behind the areola, the pigmented area around your nipple. Tickle the baby's lips lightly with the nipple and wait for her to open her mouth very wide, then pull her in close to your breast with the nipple pointing up into her mouth. If it doesn't quite work the first time, be patient and try again.

Signs of Effective Breastfeeding

Perhaps the most obvious sign of effective breastfeeding is adequate weight gain in your baby. This should not be solely relied on, however, as babies with Down syndrome often gain weight at a slower rate than traditional milestones suggest.

You cannot actually see the milk going into your baby, but here are things you can check for to ensure your baby is nursing effectively:

- The baby has taken a good-sized mouthful of breast, so that her gums can compress the milk ducts that lie behind the nipple. The nipple is drawn far back in her mouth as she sucks.
- The baby's chin is pressed into the breast and her nose is lightly resting on the breast.
- The baby's tongue is cupped under the breast. You can see the tongue by pulling down gently on the bottom lip. The tongue should be visible between the breast and the baby's gum.
- The baby's mouth has a secure seal on the breast. To release the seal when taking your baby off of the breast, try slipping a clean finger in the corner of his mouth, or press down gently on the breast near his lips.

Typically, it takes one to two minutes of your baby on the breast before let-down occurs. During this time, the baby will suck rapidly, pausing after every 3 or 4 sucks to swallow and breathe. After the let-down, sucking becomes slower and longer, with a pause between most sucks.

Listen for sounds of swallowing coming from your baby, approximately two to three seconds apart. Swallowing noises may be subtle and difficult to hear. You may find it helpful to have a partner or professional listen with a close ear the first few times you breastfeed. You can also try placing a finger lightly under your baby's chin—you should feel a delicate, repetitive movement as she swallows.

Potential Influences

There are several factors that can influence a baby's success with breastfeeding. You can trouble shoot with these tips, and reach out to a lactation team for support. If you didn't leave the hospital with a connection to a lactation team, talk to your baby's pediatrician.

Low Muscle Tone

As babies with Down syndrome often have low muscle tone, including reduced muscle strength in their tongue and lips, good head support is particularly important for your baby during breastfeeding. There are a variety of ways you can hold your baby while breastfeeding to support his head, neck, and upper back. Applying gentle, steady support to the base of your baby's head will help him to suck well without tiring. However, it is important not to put too much pressure on the back of the baby's head, as it can cause a poor latch. Here are some positions that may help:

Cross-Cradle Hold

The cross-cradle hold allows you to provide your baby good head support during breastfeeding. Hold your baby using the arm opposite the breast at which he will feed (i.e., the right arm when nursing at the left breast).

Position your hand to support his neck and head, like a shirt collar, while his body extends along the length of your forearm. The free hand will hold and position the breast. This position offers a good view of your baby at the breast and helps you to control and support both his head and body. Support the base of your baby's head so he can still tilt it back slightly. Avoid placing any fingers above his ear level.

Football Hold

The football hold also allows you to support your baby's head and gives you a good view of his face so you can watch for latch-on and sucking problems.

To feed on the right breast with the football hold, clasp your baby's torso under your right armpit. His legs will not be visible as they will be tucked behind your arm, along your side. Use your right hand to position his head to your breast.

To feed from the left breast, hold his torso under your left armpit and use your left hand to position his head onto your left breast. You will find it helpful to support your baby with a pillow at your side to ensure you and your baby are most comfortable.

Applying gentle, steady support to the base of your baby's head will help him to suck effectively without tiring; you should be supporting the upper back area and neck, keeping his head steady with your fingers below his ears.

Dancer Hand Position

Another way to physically support the baby's sucking is to use the "dancer hand" position. This position is particularly useful for babies with low muscle tone.

To do so, support your breast using the C-hold (thumb on top, four fingers underneath). Slide the hand supporting the breast forward, supporting the breast with three rather than four fingers. Your index finger and thumb should now be free in front of your nipple. Bend your index finger slightly so it gently holds your baby's cheek on one side while the thumb holds the other cheek. The index finger and thumb form a "U" with the baby's chin resting on the bottom of the "U". The "dancer hand" position keeps the weight of the breast off the baby's chin and helps him hold his head steady while nursing.

> "In the early weeks Rebecca would make gaspy, choky noises during feeds. After some trial and error, a more upright feeding position seemed to minimize this."

Milk Flow

If you find your baby seems to be drinking too quickly, position your baby "uphill" so her throat and neck are higher than your nipple. You can lean your body farther back by sitting in a rocking chair or leaning on a supportive pillow, or have your baby sit up in a straddle position on your lap. This position will help avoid gulping and coughing, which may be a problem for some babies with Down syndrome.

If your milk flows slowly or moderately, try starting your milk flow prior to putting your baby to the breast. Gently massage the underside of your breast to encourage your milk to let down. Placing a warm, damp face cloth on your nipple may also promote milk let down.

Sleepiness

Many babies with Down syndrome are very sleepy the first few weeks after birth, which can hinder their feeding routine. To establish your milk supply and ensure your baby gets enough milk, it may

be necessary to wake him to feed every two hours, or at least 8-12 times a day.

It may also be challenging to keep your baby awake for the duration of the feeding. The hind milk, obtained in the latter part of the feeding, is higher in fat and calories which are important for growth. It is important that your baby receive these nutrients. Your lactation team may also recommend a pump to help with milk supply.

Tips you may use to keep your baby awake during breastfeeding:

- Dim the room so your baby doesn't have to close his eyes against the light
- Remove his clothes before breastfeeding to keep him cool and aware
- Stimulate his senses by lightly touching the edge of his outer ear, stroking his arms, and talking to him during feeding. These touches and sounds will distract him from becoming drowsy and help him to focus on the task at hand
- Try placing a cool, damp washcloth on your baby's belly, leg, or forehead. The cool sensation is bound to wake him up

Your baby can be encouraged to continue active suckling, and get more milk, by using breast compression and/or switch nursing.

- Breast compression is done when the baby is breastfeeding but sleepy or not actively sucking. Use one hand to squeeze the breast firmly but not so hard that it hurts. The baby should start to swallow. Keep squeezing until the baby stops or slows down his sucking again. When you release the pressure, the baby will increase swallowing; once it slows down, squeeze again. Repeat the squeezing and releasing until it no longer works, and then offer the baby the other breast.
- To try switch nursing, watch for the baby to lose interest in active suckling, then slip a finger in the corner of his mouth to break the suction and offer the other breast; he should nurse more vigorously. When his sucking slows again, switch him back. Keep repeating this until he seems satisfied. You can combine breast compression and switch nursing or do just one or the other. You will see what works best for your baby.

Tongue Thrust

Babies with Down syndrome may have a protruding tongue that can push against your nipple. This may pose a challenge for your baby when latching on, as he may push the nipple out of his mouth. If your baby is latched on properly, you should be able to see his tongue cupped under the breast, resting on his lower gum.

> "I was encouraged by the Early Intervention Center to breastfeed because it helps with lip closure and discourages tongue thrusting as the child gets older."

When you are latching your baby onto the breast, watch for his mouth to open wide, with his tongue forward and down. To encourage your baby to bring his tongue forward, use your index finger to press down softly on the baby's chin while he latches on. This opening of the jaw will cause the tongue to protrude further out of his mouth.

Don't be disheartened if your baby needs some initial encouragement to keep his tongue down while latching on. Facilitating oral stimulation can help move the tongue into position to breastfeed. To do so, place your index finger on the center of your baby's tongue, encouraging the tongue to form the shape of a trough. Push down on his tongue while gradually pulling your finger out of his mouth. Try repeating this exercise several times before latching your baby onto the breast.

Weight Gain & Supplementing—if your baby needs a little more support

As we said above, the most important thing in these early weeks is that your baby is getting adequate nutrition. Remember that every baby is different, and one size does not fit all; there are no hard and fast rules! Your family physician or lactation consultant will be able to offer you guidance on what techniques will work for you and your baby.

During the time that your baby is learning to breastfeed effectively, you may need to offer supplements after most feedings. Some babies nurse better if they get some of the supplement before they are put to the breast, rather than waiting until they are upset with hunger.

You and your healthcare team will be monitoring your baby's weight gain. Four ounces a week is considered adequate weight gain, but it is not unusual for a baby with Down syndrome to gain slowly even when she is receiving enough nourishment. If she is not being given anything but your milk, a baby who is getting enough to eat should have six really wet diapers (more if using cloth diapers) and three to five bowel movements a day (beginning after the fourth day). An older baby may have bowel movements less frequently, but they should be plentiful.

A baby who is not nursing effectively or long enough may not be getting the hind milk, the high-calorie milk that comes toward the end of a feeding. Sometimes using breast compressions , massage or switching sides twice during the feeding will help your baby to obtain that higher calorie milk. If that doesn't enhance the baby's intake and weight gain, you can offer this hind milk as a supplement after your baby has finished nursing, to ensure she is receiving all of the nutrients.

If you choose to offer your milk as a supplement, there are a variety of methods for you to choose from. If your baby can latch and needs supplements of either expressed human milk or formula, you can use a nursing supplementer or other method that avoids artificial nipples. The nursing

supplementer is a small soft tube that rests on the breast like an "outer" milk duct. This method is helpful because the baby suckles at the breast while receiving the extra flow of milk from the small tube. It is better to avoid giving supplements in a bottle until your baby has been breastfeeding well for three to four weeks. While she is learning how to breastfeed, exposure to artificial nipples and a different type of milk flow may cause nipple confusion, since sucking at the breast is different than sucking on a bottle. If your baby is struggling to latch on, ask your lactation team about the use of a nipple shield while supplementing. For some babies, this is a great way to get milk with less effort, while still being exposed to the breast.

Bottles are difficult to avoid if the baby is unable to maintain an effective suckle at the breast. The need for bottles may diminish as your baby matures and his muscle tone improves, and some mothers have found ways to bottle-feed in a manner that supports breastfeeding.

> "The fact that I was able to breastfeed my exceptional baby helped bring everything back into equilibrium again. In a mother's eyes, the imperfections fade and the child shines through and you see that, after all, he is a real little human being."

A few last words:

We provide this information to you because in the past, doctors have presumed that babies with Down syndrome cannot nurse, and consequently many babies are deprived of the opportunity to try. That being said, it's important to remember that there are many situations that can make breastfeeding difficult or impossible, from the baby's developmental or medical needs, to postpartum health of the mother, to adoption, to complex family situations. If that's the case for you and your baby, please know— your baby will be OK! You can often get the cost of a high-quality breast pump covered by insurance, if pumping is in the cards for you, which will allow your baby to enjoy the many known benefits of your milk as their first food. If pumping isn't possible for your family, you can rely on high-quality infant formulas, or even look for a breast milk bank. Work with your doctor to make the best decision for your family and your situation, and know that your baby will be fine whatever way they get their first nutrition!

When to feed your baby

Learn to recognize the signs that your baby is starting to wake (eye movements behind the lids, mouth and body movements). Your baby may be very sleepy; he may need to be woken for feeding and stimulated to keep him awake while he feeds. Babies will feed better if they are awake and hungry and not crying. Crying is a late sign of hunger and if your baby is distressed, it may be difficult for him to attach properly to the breast. He may tire quickly, so will need to feed when he has the energy to do so.

You can wake your baby by:

- Unwrapping him, talking to him and moving him around.
- Changing his diaper, rubbing the soles of his feet vigorously, patting his legs with a cool cloth (in cold climates this may not be practical and you may find other methods more suitable).
- Using a method known as the Doll's Eye Technique. This involves laying your baby on your lap with his legs towards your stomach. Support his head and body on your hands and arms, then sit him up by bending him at the waist. Lay him down again while talking to him. Lift him again and repeat this until he opens his eyes and keeps them open. Then put him to your breast.
- You may need to burp your baby and swap him to the other breast several times during a feed to keep him roused.

However, some babies do not feed well if woken. It may be better to wait until he wakes of his own accord and try to ensure that he has a substantial feed then.

> "The most successful way to wake him was to give him a shower. He enjoyed the showers and would always feed well afterwards."

Taking care of yourself

Feeding your baby will take a lot of time no matter which method you choose, so it is very important to take care of yourself. When you are at home with your baby, make sure that you have a comfortable place to sit so that you can relax while feeding. Move the phone close to you or ignore it so that you are not disturbed by calls.

Accept any offers of help with meals or housework. This is not always easy, but those who offer genuinely want to help. This will free your time for caring for your baby.

If your baby is hospitalized

If your baby needs special medical care after birth, breast feeding will be more complicated, but still may be possible, depending on your situation. Even if your baby needs surgery or is admitted to the neo-natal intensive care unit (NICU), you may be able to pump and provide the milk to the hospital team to feed your baby with, either through bottles or a feeding tube.

Just remember, you are a critical part of your child's care team, so if something is important to you, don't forget to speak up.

Expressing your milk for tube feeds will help to establish and maintain your milk supply. As his strength and health improves, you will be able to try some breastfeeds; slowly at first, then gradually building up to full feeds. ABA booklets Expressing & Storing Breast Milk and Breastfeeding Your Premature Baby contain suggestions that you may find helpful.

If your baby must return to the hospital for surgery, it is important to plan ahead if you intend to continue to breastfeed. Talk to hospital staff and your child's doctor, explaining that you are breastfeeding and see if you can be accommodated along with your baby. Discuss with your baby's surgeon and anesthesiologist how long your baby will have to fast before surgery, and how soon afterwards he will be able to resume breastfeeds. Some mothers find they need to express their milk for a few days until their baby is well enough to feed at the breast again

Expressing in this situation relieves the discomfort of overfull breasts and helps to maintain your milk supply. If your baby has a heart condition requiring surgery, you will probably find that after surgery he is much stronger, and more able to stay awake for feeds. ABA's booklet Breastfeeding & Hospitalization may be helpful. You may also contact a lactation consultant, nurse, doctor, or hospital about hiring electric breast pumps. Many mothers find electric pumps very helpful if they are expressing over a long period of time.

In conclusion

When suggestions are listed like this, they may seem rather daunting and you might feel that you face an impossibly difficult task in attempting to breastfeed your baby. Remember that it is unlikely that all situations here will apply to your baby. Try the suggestions that seem to suit your baby's needs and use those that help. You will probably find your own ways of overcoming difficulties as you get to know your baby. Also remember that most difficulties will resolve as your baby learns to breastfeed. It is in the early days of establishing breastfeeding that your baby is most likely to need extra help. Breastfeeding your baby may not be easy at first, but as he grows he will become stronger and more able to feed effectively.

EATING & NUTRITION

Getting used to eating is a challenge for most babies. For babies with Down syndrome, like many other things, it can be a bit more challenging and may take more time, both for individual feeding sessions and to meet various feeding milestones. But don't despair! Your baby will learn to eat.

There are many articles and resources out there about how to meet the nutritional needs of babies and children with Down syndrome. In the past there have been claims of nutritional "cures" for Down syndrome, but these claims have not held up. It is worth a mention here to read with a critical eye. If it sounds too good to be true, it probably is.

Below is an article called "From Milk to Table Foods: A Parent's Guide to Introducing Food Textures", written by Joan Guthrie Medlen, R.D., L.D. and reprinted from the Jan/Feb 1999 issue of the Disability Solutions newsletter.

Joan was once in your shoes—a new mom with a baby boy with Down syndrome who didn't want to eat. Joan's son is now an adult, and Joan is a nationally-recognized expert in the nutritional needs of children with Down syndrome and, just as important, an expert in how to teach your child to eat. She is also the author of the definitive reference, *The Down Syndrome Nutrition Handbook*, which is available from Phronesis Publishing (downsyndromenutrition.com/phronesis).

The Down Syndrome Nutrition Handbook has a great deal of information about nutrition and healthy living that extends from the infant/toddler years into adulthood.

Before reading further, a word of caution is appropriate: things will get messy, just as with every baby. But once you accept it, that mess can be the start of some real fun as you explore different food types together.

"From Milk to Table Foods: A Parent's Guide to Introducing Food Textures" includes specific information regarding the process of learning to chew foods and how to tell when it is time to begin to introduce new textures to your child with Down syndrome based on ability, not age. There are also tips to help teach your child how to chew and some suggestions for problem-solving common rough spots.

If after reading this article, you are wondering if you should seek the help of a feeding team, here are some questions to consider:

- Am I talking to more than one or two professionals about feeding (for instance, what foods my child eats, oral motor skills and exercises, or other medical conditions that affect feeding)?
- Am I getting advice from more than one or two professionals about feeding that is difficult to blend together or is conflicting?
- Is my child's eating or feeding taking a lot of time and therefore a lot of time away from other family members?
- Is my concern about my child's eating or feeding taking time away from family due to stress or worry?
- I would like to have one, concise plan for helping my child learn to eat different textures and participate in family meals (yes/no).

If you answered yes to two or more of these, it is strongly recommended that you seek out a feeding team in your community. Feeding teams consist of a multidisciplinary team dedicated to solving concerns about eating and feeding. They are usually associated with the children's hospital in the area.

"From Milk to Table Foods: A Parent's Guide to Introducing Food Textures"

Learning to eat foods, from the first bites of baby cereal to regular table foods, is a long process. For children with Down syndrome, learning to coordinate tongue and mouth movements takes longer and can cause parents concern. It helps to understand the developmental stages and skills children must go through learning to chew. This article discusses what chewing skills to look for before changing the texture of food and how to encourage and teach your child with Down syndrome to chew different foods. With this information you can sit back and enjoy the fun and messiness of discovering foods together with your child.

There is little information available to parents explaining what to look for when introducing new food textures to children with Down syndrome. Most information is written for children without disabilities and presents the introduction of different food textures as an age-related table. The ages for different types of foods (strained baby food, pureed, ground, chopped foods) reflect the typical age that certain tongue and jaw movements develop. Some children with Down syndrome will follow these tables and have little trouble with the introduction of foods, or chewing. Others will experience delays because of lower muscle tone or a smaller mouth cavity. Understanding chewing development and the key tongue and jaw movements that signal readiness for a new food texture—such as going from strained, pureed foods to thickened, pureed foods—is essential to the process (Table 1).

Before your baby is offered her first bite from a spoon, she is getting her food through breastfeeding or from a bottle. The mechanism for swallowing during that time is called suckling, which is a combination of extension and retraction of the tongue, forward, and backward jaw movements, and a loose closure, or connection, of the lips around the nipple.

Throughout those first months of breast or bottle-feeding, your baby builds strength in her tongue and mouth and a new pattern begins to emerge which is called sucking. Sucking includes a more rhythmic up and down jaw movement, an elevation of the tip of the tongue, and a firm closure of the lips around the nipple, which creates a negative pressure in your baby's mouth. It is usually shortly after this sucking period begins that the first bites of baby food are introduced, commonly between four and six months of age.

That first bite of baby cereal is a big event for everyone involved. Not only is it a new developmental stage, but also it is a change in the relationship between your baby and everyone around her. Eating requires more participation and interaction from her. Those who feed her will learn to listen to her cues regarding how fast or slow to present each bite. In these early interactions the groundwork is laid for other give-and-take situations. It is a natural time for parent and child to develop an awareness of overall body tone, stamina, and to develop a feeling of mutual trust and respect.

Those first bites of baby cereal are also very messy. Generally, babies will lose a certain amount of the cereal as they try to coordinate their tongue and jaw movements to this new, foreign food. Babies with Down syndrome often lose more food than those without Down syndrome with these first bites. If too much food is lost, your baby's jaw movements may still be more of a suckling pattern—tongue and jaw thrusts resulting in loss of food—than a sucking pattern.

A good rule of thumb to use is if your baby with Down syndrome seems to be losing 75% or more of the food from each bite, it might be best to wait a few days and try a bite of cereal again. Once she is eating baby cereal successfully, follow the typical pattern for introducing first baby foods. This category of foods is called strained, pureed foods, which includes baby cereals; jarred, strained baby foods; and homemade, pureed, strained foods.

If your baby continues to lose a lot of food with each bite due to jaw and tongue thrusts, there are some things you can do to help her learn to control her mouth and tongue while eating:

- Check your child's positioning. The best position is as near a sitting position as possible, with her legs, head, back, and feet supported as needed.
- Your baby should be able to look straight ahead at you or the person feeding her during her mealtime. Looking up to see the person feeding her causes her to lift her head back and makes swallowing more difficult.
- Spoonfuls of food should be small. Too much food makes the process more tiring and frustrating for both of you. It is easier to move a small amount of food around in her mouth than a large one.
- Present the spoon from slightly below your baby's mouth. As she accepts the spoon, place the bowl of the spoon firmly (but do not push hard) on the center-front of her tongue. This helps her keep her jaw and tongue from thrusting forward.
- Remove the spoon straight out of her mouth (do not lift the spoon to scrape food off). This will encourage her to use her lips to close around the spoon to get the food.

- Watch your baby's cues. Learning to handle food is not easy. Wait for her to completely finish her bite before offering her another. It may take her extra time to coordinate her movements between bites. Watch for her receptiveness for each bite rather than providing the spoonful of food before she is ready.
- Watch for signs of fatigue. Tiring early in a meal is very common for children with Down syndrome, particularly in the beginning stages of eating. Try not to push her past her limit to frustration. If she tires too early to get enough calories, consider more frequent meals (6-8 times in a day). Focus on increasing the length of each meal until one or more can be eliminated from the daily schedule without sacrificing calories. Give yourself and your baby some time together at this stage.

Table 1: Chewing development with suggested food textures

Food type	Chewing stages	Skills to note	Food to offer	Indications for next step	Precautions
Pre-Food	Suckling	Rooting	Breast milk or formula	Beginning of sucking motion	
Puree	Sucking	Tries to hold bottle, Decrease in gag reflex.	Infant cereals should resemble heavy thick liquid or applesauce. Other foods: blended, strained, baby foods (jar or homemade)	Strong, well-developed sucking motion	
Thick Puree	Strong sucking, early munching	Interested in "guiding" spoon	Gradually increase thickness with baby cereal, wheat germ, potato flakes. Provide teething foods (pretzels, toast, etc)	Up-and-down chewing motions	Monitor for choking
Ground	Munching	Decreased gag reflex. Increased use of cup. Grasps and plays with spoon	Mashed, cooked vegetables, scrambled egg, mashed soft-boiled egg, cottage cheese	Side-to-side movement of foods with tongue	Don't mix textures (such as spaghetti with meat balls, peas in mashed potatoes)
Chopped Foods	Chew progresses to mature rotary chew	Assists with feeding and drinking with increasing independence	Chop regular table foods in small pieces. Introduce finger foods that are easily chewed	Individualize for preferences and abilities	Avoid easy-choke foods
Table Food	Well-practiced at mature rotary chew	Messy self-feeder, switches between utensils and fingers			Monitor easy-choke foods. Modify list as needed. Introduce crunchy and chewy foods to build jaw strength

Some children will have tongue-thrusting movements and continue to lose food as they eat. If she is eating her foods without coughing or gagging, then she has most likely found a way to adapt her tongue movements. If she is coughing, gasping, gulping, or gagging after most bites of food, check with your doctor or speech pathologist to make sure she is swallowing safely. As your baby gets accustomed to strained, pureed foods, she will begin to develop a strong sucking action.

Once your baby is proficient with strained, pureed foods, which you can tell by the stronger sucking action, it is time to begin thickening her foods. While eating these thickened, pureed foods your child learns to use her tongue to move food in her mouth. To thicken foods, add instant potato flakes, wheat germ, breadcrumbs, or dry baby cereals. Using wheat germ to thicken foods is also an excellent way to increase fiber. When you thicken strained, pureed foods, there are a few things to remember:

- Foods will continue to thicken after you are done mixing. Check the consistency of the food every three bites or so. You may need to add some liquid so it doesn't become too pasty.
- Use a thickener (baby cereal, potato flakes) that makes sense for the food you are thickening. Strained pears with potato flakes have a funny flavor. Rice cereal might be a better choice because it has a less distinctive flavor.

During this stage (thickened, pureed foods), your child will develop what is called a phasic bite reflex which is a rhythmic bite and release pattern that looks like she is opening and closing her mouth when something touches her gums (a toy, a spoon, some baby food, or your finger). This is a good time to let her explore with a spoon or an empty cup. Although this stage does not signal time to change your child's food texture, it is an important step to being able to accept different textures. Allowing her to chew on things such as washcloths and toothbrushes help her get used to the feeling of different textures in her mouth. This is helpful later when she is trying out new and different foods.

The next chewing stage to look for is munching, which is when your child moves food in her mouth by flattening and spreading her tongue while moving her jaw up and down. For some children with Down syndrome, this may look something like a flattening on the roof of the mouth followed by a pushing outward of the tongue to move the food as she opens her mouth.

When you see she is beginning to munch, it is time to introduce some finely ground foods, such as cooked, mashed vegetables, scrambled eggs, or cottage cheese. This is your child's first experience with texture in her food. She may be surprised or react strongly. Be prepared for a lot of messes. If she rejects a food (throws it, spits it out, smears it all over), don't take it personally. Offer a small amount again in a few days. Eventually the food will make it to her mouth.

It is not uncommon for children with Down syndrome to continue to struggle with low oral motor tone at this stage. Some children may find ways to move foods with their tongue that are slightly different from what is considered "typical." Again, if your child is choking, gasping, or gagging a lot, ask for help from your doctor or speech pathologist. If, however, she is handling foods without choking or gagging, but is having trouble coordinating her chewing or tongue, here are some things you can do to help encourage her eating skills:

- During a meal, sit directly in front of your child. Place your thumb on her chin below her lower lip. Your index finger will be back by the joint of her jawbone and your middle finger under her jaw behind her chin. Gently encourage her jaw movements in an up and down action. Do not force this movement. If she protests and asks you to remove your hand, it's best to respect her wishes.
- Place food (scrambled eggs and small graham cracker pieces are good) between her gums or molars on one side of her mouth. This encourages her to move her tongue to get the food.
- If your child seems to prefer to chew on one side of her mouth, place food on the other side. This works especially well if it is a favorite food.
- Offer toasted bread strips, strips of soft cheese, and other appropriate finger foods. It is safest to hold on to one end of the food as she chews so she doesn't get too much at once.
- Do not mix food textures! Foods that have more than one type of texture such as Spaghetti-Os, most junior foods (spaghetti with meatballs) or lumpy ground foods require different chewing movements. It is confusing to your child to have more than one texture to deal with at a time in a bite of food.
- To encourage her to move her tongue from side-to-side (a skill needed for rotary chewing), offer ice cream cones to lick and vary the position of the cone, or place small dabs of smooth peanut butter in the corners of her mouth to lick off.

When your child is able to move foods from side-to-side with her tongue, it is time to introduce finely chopped foods. Use foods from the family meal that you chop very small. It's best to begin with foods that are easy to chew, such as chopped pasta, cooked vegetables, cooked potatoes (without the skin), or canned or very ripe fruits. Let her watch you remove her food from serving dishes so she sees it is the same as what the rest of the family is eating. This usually makes these new foods particularly interesting to experiment with and eventually eat. As she becomes comfortable with finely chopped foods, gradually increase the size of her foods to bite-sized pieces.

During this time, your child will slowly work toward a mature rotary chew, which uses the tongue to move food from side-to-side in the mouth along with a coordinated movement of the jaw in vertical, lateral (side-to-side) and diagonal movements. A mature rotary chew looks like a smooth, circular motion while the jaw opens and closes to chew. For many children, with and without Down syndrome, this is easy to observe because it is difficult to do with their lips together, eliciting the familiar comment, "chew with your mouth closed!"

For children with Down syndrome, it is quite helpful to understand what your child is learning to do as you introduce new food textures. Rather than using age to decide when to introduce a new texture, watch your child eat and look for the skills she needs to progress.

It takes children with Down syndrome longer to chew their food, which continues for many years or may be lifelong. This could be because of low oral motor tone, motor planning (coordinating the movements to do the chewing), or from general fatigue from the work of eating. Regardless of the reason, it is something to keep in mind at meal times, particularly as you help her learn to eat. It may also be something to consider at day care, preschool, and as your child enters school; she may need more time to eat her lunch and snacks.

Foods to Watch

Some foods require caution for any child who is still learning to handle foods in her mouth. Children with Down syndrome often need to be cautions with these foods until age 5 or beyond. If your child has not yet mastered a "mature rotary chew," only offer these foods with strict, attentive supervision (or not at all).

Hard, small foods	Nuts, seeds, popcorn, raisins, hard candies, raw carrots, chips, snack puffs
Slippery foods	Whole grapes, hot dogs, sausage, olives, large pieces of meat

Learning to eat foods and progress through textures is more than developing chewing and swallowing skills. As with most things, there will be times of frustration along with joy in accomplishments. When you are feeling frustrated, here are some things to remember that may be helpful:

- Learning to eat is a messy process. However, a lot of learning takes place in the midst of the mess. While exploring food, children learn about the feel, smell, and temperature of foods (and sometimes the sound as they plunge to the floor).

- Children with Down syndrome often take longer to progress from baby food to regular table foods. However, that doesn't mean you have to forfeit table manners. Your child is learning about table manners from everyone around her. It's a great time to remind others to eat politely and to encourage the same, when appropriate, for your child with Down syndrome.
- Try to make mealtime pleasant. Learning to eat, use utensils, and try new foods is a lot to do. Children with Down syndrome may become overwhelmed if too much is going on around them during mealtime. Try to limit the amount of extra activity where your child is eating or at your family table by turning off the television, radio, video games, etc.
- Remember your child is always growing. The seating position that is best for your child will change as she grows. It is most important to consider upper body support and a place to rest her feet so her knees are at a 90-degree angle. These two things will affect her ability to feed herself as well as her ability to chew and swallow safely. If she has to add the work of supporting her upper body or her legs while eating, she will not want to also work on using her spoon or fork.
- Eating takes time for children and adults with Down syndrome. It is worthwhile to allow for extra time whenever possible.
- Offer new foods one at a time. As your child grows, continue to introduce new foods along with old favorites. Do not force her to try "just a bite." Instead, offer a small amount over the course of many meals. Consider it a side dish. Eventually she'll give it a try.
- Establish a family mealtime. Whenever possible, even as a baby, include her in the family mealtime so she can see how others eat and talk with each other. Try to serve foods that are as similar to what the rest of the family is eating (either in color or type of food) as possible.

There are times when, despite your best effort or because of medical complications, your child with Down syndrome may not be moving from baby cereal to table foods in the way you expected.

Early Intervention Team members are available to answer questions. Each team usually has a speech pathologist and an occupational therapist, and some will have dietitians who all are familiar with feeding concerns. In some cases, it may be necessary to consult specialists. If you are unsure if you need to consult a feeding team, ask your pediatrician or call a clinic that specializes in treating children. Ask to speak to a pediatric dietitian or the feeding team.

Learning to eat is a delightful time for parents and children. It's a time full of new experiences and creative ways to explore foods, utensils, and the reactions of others. Understanding when and why to introduce new foods to children with Down syndrome makes it possible to move forward while you relax and enjoy the messes together.

My life is like team sports

By Daniel Jarvis-Holland

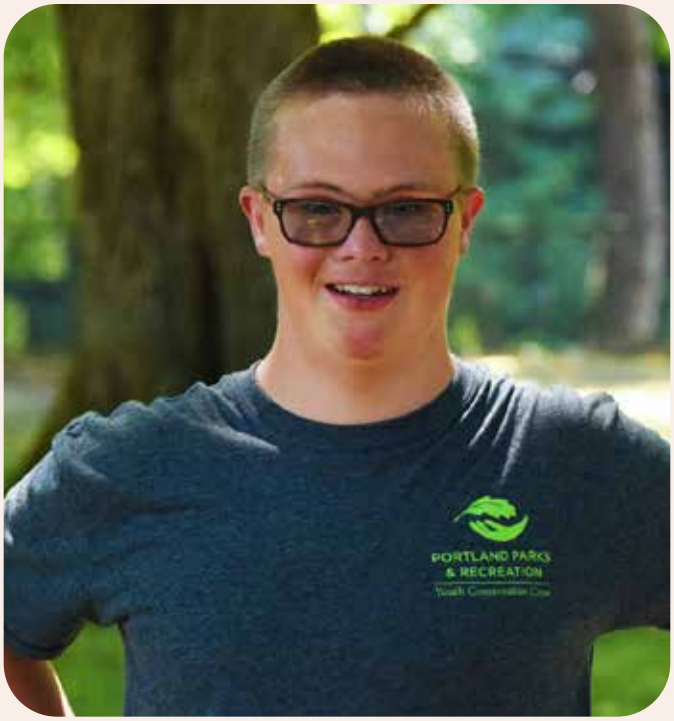
My family is a great team. They take care of me and teach me things. I take care of my family classmates and teachers. I love them, my school is part of my family.

I like the Trailblazers, they are great at defense and they protect each other. Everyone has an important role and they support each other. They always stay together.

Magic Johnson was a great team player. He could help by making everyone around him better.

Sometimes his teams won and sometimes they lost, but they worked together. Magic was on the 1992 Olympic "dream team, that won the gold. Every family can be a dream team.

Teams and families spend a lot of time together. They have to work hard to sup-port each other and be patient with each other.



Sometimes they get mad at each other, but they also get to have fun with each other. This is part of growing closer and building bonds.

Teams work because everyone on a team has different strengths and weaknesses. Each person compliments each other, which helps build a good team. We are all different races, sizes and ages but a community is one big family.

The best thing about teams and families is they have shown me that it is always better to be together.

I have a lot of dreams for my future. I want to make videos. I want a girlfriend. I want to go to college.

Then have a job or my own business, a coffee shop and cartooning space and gallery.

I will need more people on my team to make this happen.

When we are all part of a team we can take care of each other and be stronger.

[Update: Daniel graduated from high school and took college classes at Portland State University and Portland Community College. He is a strong advocate for inclusion.]

RESOURCES

Early Intervention resources in Portland Metro & SW WA

Early Intervention (EI) is a set of free, specialized services provided to children ages birth to 5 years of age with developmental disabilities and delays, including those with Down syndrome. It is a federally-mandated program that is implemented at the county level. Local counties, school districts or education service districts provide the services.

Eligibility

All children with a Down syndrome diagnosis are eligible to receive EI services. Your child will still need to have an evaluation, but the Ds diagnosis guarantees they will qualify.

The basic process includes the following steps:

Services offered

Once your child has received an evaluation, the types of services offered may include but are not limited to:

1. Referral
2. Screening
3. Evaluation for eligibility
4. Determine eligibility
5. Individual Family Service Plan
6. Placement

The services that your child receives is determined by the recommendation of the Individual Family Service Plan (IFSP) team members. Services will vary depending on where you live and may be provided in a variety of settings.

- Parent consultation/education
- Gross and fine motor therapy
- Speech therapy
- Occupational therapy
- Vision services
- Hearing services
- Early Childhood education services
- Assistive technology services

Multnomah County, OR
Multnomah Early Childhood Program (MECP) Referral Line: (503) 261-5535
Website: ddouglas.k12.or.us/departments/multnomah-early-childhood/

Clackamas County, OR
Clackamas Education Service District Early Intervention Referral Line: (503) 675-4097
Website: clackesd.org/departments/early-learning/

Washington County, OR
Northwest Regional Education Service District Early Intervention Referral Line: English (503) 614-1446; Spanish (503) 614-1299
Website: nwresd.org/departments/early-intervention-early-childhood-special-education-ei-ecse/early-intervention-and-early-childhood-special-education

Other counties in Oregon
Find the Early Intervention/Early Childhood Special Education (EI/ECSE) services in your county by visiting oregon.gov/ode/students-and-family/specialeducation/earlyintervention

Clark County, WA
Washington State Department of Children, Youth & Families Early Support for Infants and Toddlers (ESIT) Referral Line: (360) 750-7507
Website: dcyf.wa.gov/services/child-development-supports/esit

"There are two ways of exerting one's strength; one is pushing down, the other is pulling up." -Booker T Washington

Other Resources

These national organizations will send free, accurate information about Down syndrome to you and other family members. Many groups have yearly conferences, newsletters, and lists of local parent groups who you may wish to contact for local resources and information.

The Arc of Multnomah/Clackamas
thearcmult.org • (503) 223-7279

National Down Syndrome Congress
ndsccenter.org • (800) 232-6372

National Down Syndrome Society
ndss.org • (800) 221-4602

National Association for Down Syndrome
nads.org • (630) 325-9112

RECOMMENDED BOOKS

Count Us in: Growing Up with Down Syndrome
By Jason Kingsley and Mitchell Levitz — Mariner Books, 2007

Babies with Down Syndrome: A New Parents' Guide
Edited by Susan J. Skallerup — Woodbine House, 2008 (Also available in Spanish)

A Parent's Guide to Down Syndrome: Toward a Brighter Future
By S.M. Pueschel — Paul H. Brookes Pub. Co., 2001

Early Communication Skills for Children with Down Syndrome: A Guide for Parents and Professionals
By Libby Kumin, PhD, CCC-SLP — Woodbine House, 2003

Down Syndrome: The Facts
By Mark Selikowitz — Oxford University Press, USA, 2008

Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals
By Maryanne Bruni, BScOT — Woodbine House, 2006

Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers
By Patricia Logan Oelwein — Woodbine House, 1995

Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals
By Patricia C. Winders — Woodbine House, 1997

We'll Paint the Octopus Red
By Stephanie Stuve-Bodeen, Pam DeVito — Woodbine House, 1998

RECOMMENDED WEBSITES

Sibling Support Project — siblingsupport.org

Inclusion Home Page — inclusion.com

Institute on Community Integration — ici.umn.edu

Down Syndrome Research Foundation — dsrf.org

Down Syndrome Health Issues, Dr. Len Leshin — ds-health.com

Notes from Parents

"When telling relatives and friend that our much-wanted first child had Down syndrome, we knew that they would find the news sad and we broke it too them gently. Our son has been accepted and visited by all."

"By the time the test results confirmed that our son had Down syndrome, he was already a part of our family and we could not consider anything other than keeping him with us."

"When our little girl was born with Down syndrome, it was a terrible shock and we were very sad. Our parents and friends were very supportive, which helped enormously. One of the most helpful things was being introduced, through the local Down Syndrome Association group, to a family with a nine-month-old daughter with Down syndrome. Meeting them showed us that we would be able to cope and even enjoy life with a child with Down syndrome."

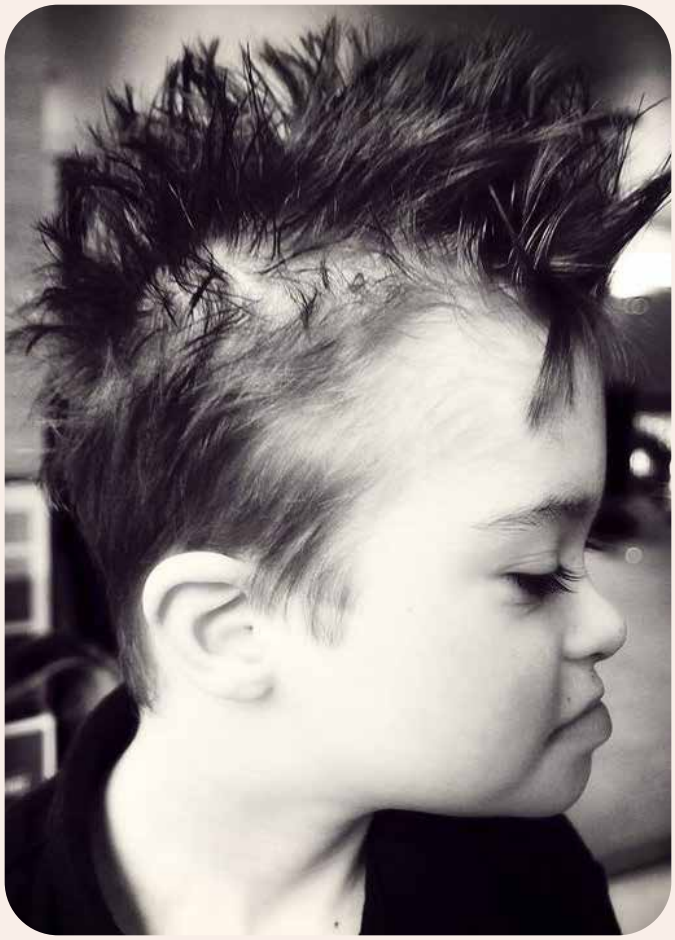
Siblings Speak

"When my little sister was born, Mommy and Daddy told me that she would be a bit different and would need help to learn things, more than I did. She can do lots of things and I take her out to play. I think she is lovely." Angela, 12

Grandparents Have the Last Word

"One of my friends reminded me recently that when I told her that my daughter's first child had Down syndrome, I said my life would never be the same again. After 11 years I can say that what I said then has been true, not in quite the negative sense that I might have anticipated, but in the richness of the experience we have had in watching our grand-daughter grow and develop." Lucy's Grandma

"I feel moments of sadness when I think how much help Timmy needs compared to my other grandchildren, but bit by bit I can see him get up to the same tricks that the other children have got up to and I know I am really glad to have him as a part of our family."



[Editor's Note: children with Down syndrome develop at a slower rate than children that do not have Down syndrome, but they do develop, they do learn, and they will do most if not all of the things that all children do—it just takes a little more time, that's all.]

Who Are You?

By Michael Bailey
Used with the permission of The People First Connection: the voice of self-advocacy in Oregon

You came before me

And now I stand on your shoulders.

Were you scared?

Scared, when you questioned every decision that you make?

Scared, when you wondered if they were right and you were wrong? Scared, when you knew what needed to be done for a quality life.

Where did you find your strength?

Strength, to get out of bed.

Strength, to attend another "Can't" meeting. Strength, to believe in yourself and to believe in your child.

Did you cry as often as I do?

Cry, when the simplest tasks are mastered?

Cry, at the bigotry of this world? Cry, when you heard, "I love you" for the first time?

Were you angry?

Angry, that every decision you make is questioned?

Angry, that people only see differences, not sameness? Angry, for being put on this path?

Did you laugh?

Laugh, when others were horrified? Laugh, to save your sanity?

Laugh, when you knew you were in the presence of a miracle?

Where did you find your vision?

Vision, of a world that could be different.
Vision, of a world that should be different.
Vision, of a world that would be different.

To you I say Thank You.

For making decisions that scared you,

For using your anger,

for being strong, for laughing, for crying and for having the vision.

It is because of you that I know our children have a chance.

A chance, to be educated.

A chance for meaningful employment.

A chance to be valued members of their community.

REFERENCES

A Note on Language Usage

Every effort has been made to use 'people first' language in this guide. For example, rather than saying, "we have a Down syndrome child", it is preferable to say, "we have a child who has Down syndrome." We no longer refer to children that have Down syndrome as mentally retarded—what they have is a cognitive disability. This may seem picky, but the use of language in our society is extremely powerful and will affect how our children are looked upon and treated.

Disability is Natural! Revolutionary Common Sense

By Kathie Snow, disabilityisnatural.com

"Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society."

The Developmental Disabilities Assistance and Bill of Rights Act

Read it again—especially the first nine words: "Disability is a natural part of the human experience." There have always been people with disabilities in the world, and there always will be. Like gender and ethnicity, disability is simply one of many natural characteristics of being human. One in five Americans is a person with a disability. Some are born with disabilities; others acquire disabilities through accidents, illness, or the aging process.

Many folks who do not presently have a disability will have one in the future (especially if we live long enough). How can disability not be natural? When we internalize the belief that disability is natural, and merge it with our common sense, we will create a new paradigm of disability. Today's conventional wisdom sees disability as an abnormality that needs to be fixed or remedied, to enable the person to achieve an "able-bodied standard" of "normalcy."

For generations, society has embraced this arrogant perspective and as a result, children and adults with disabilities have been incarcerated in institutions and other segregated settings (including public school special education classrooms); told they're "not ready" for inclusion in school, at work, and in the community until they've achieved a level of "readiness" as defined by professionals and others; been manipulated (physically, mentally, and emotionally) in therapies, special programs, and interventions; and, in general, been prevented from experiencing real lives.

The lives of many children and adults are aberrant, but not because of the disability. Their lives are abnormal because of all the "help" they receive when client hood replaces citizenship. Many individuals with disabilities do not experience the ordinary (but precious) activities of being children, brothers or sisters, employees, friends, volunteers, or the many other typical roles and opportunities taken for granted by most Americans. The disability has defined who they are, and treatments and services to address the "problems" of the disability become the focus of their lives. Is there anything more unfair: to dehumanize people in the name of "doing what's best" for them? How many individuals with disabilities have asked to be segregated, treated, poked and prodded, excluded, or told they don't meet someone else's definition of "normal?"

How many—if given a choice—would continue in the role others have carved for them as "clients?" Who are we to invoke our standards on others? How dare we assume the mantle of superiority over women, men, girls, and boys who just happen to have disabilities! When we believe disability is natural, we'll recognize that having a disability simply means a person has a body part—legs, arms, eyes, ears, brain, or something else—that works differently. That's all!

We'll know a disability cannot define a person's potential, humanity, or character. We'll know people with disabilities don't need to be "fixed" or "treated," to "minimize the effect of the disability" or to achieve an "able-bodied standard." Instead, we'll know that tools (assistive technology devices), accommodations, and support—not achieving normalcy or an artificial level of readiness—are what people with disabilities need to be successful. And these are the same things we all need.

People without disabilities need tools (computers, electricity, telephones, and other devices), accommodations (each of us receive and/or create these for ourselves every day), and support (from family members, co-workers, friends, and others). People with disabilities are more like people without disabilities than different. And if the needs of a person with a disability are different from the so-called norm, this shouldn't wreak havoc in his opportunity to lead a normal, ordinary, and fulfilling life.

After hearing that people with disabilities don't need to be "fixed," someone invariably asks, "But my child needs surgery [or something else]—are you saying people with disabilities don't need medical care?" Of course not! I'm not implying we should forego necessary medicines, treatments, and/or surgeries. But we must rethink interventions, treatments (including physical, occupational, and other therapies), and specialized programs. All of these can have profound and negative effects on children and adults with disabilities and their families. They send the clear and spirit-killing message that the individual receiving the treatment is "not OK," and this message wounds again and again, each and every time the person is "treated" or "served."

Specialized services also foster dependency on the system and rob people with disabilities and their families of self-reliance, freedom, self-determination, privacy, and autonomy. When parents have the system to depend on, many frequently lose confidence in their ability to successfully parent their children. Children whose parents are dependent on the system learn by example, and they grow into adults who are dependent on the system. In addition, dependence on the system causes many to unintentionally cut themselves off from the natural supports and generic services that exist in their communities.

Why should one go to family, friends, neighbors, and typical resources in the community for help when there's a system that promises mandated entitlements? But as many of us know first-hand, the system is unable to meet the needs of people with disabilities and families. Still, we continue banging our heads against the brick wall, advocating for more services, increased funding, and other changes in the system—not realizing that a veritable garden of natural supports is already growing in our own back yards.

We just haven't seen them because we're lost in the maze of entitlements, laws, programs, and special services. Karate, ballet, T-ball, and other community activities can replace physical and occupational therapies. Being with typical children is the best speech therapy in the world. Neighborhood preschools, instead of special ed preschools, help.

We must never permit a person's potential or abilities to be defined by the label, for none of us has the right to steal another's hopes and dreams! Disability is Natural!

References for the sections on breastfeeding, eating, and nutrition

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The Down Syndrome Nutrition Handbook: a guide to promoting healthy lifestyles, Medlen, Joan E. Guthrie, Woodbine House, 2002.

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"We need to give each other the space to grow, to be ourselves, to exercise our diversity. We need to give each other space so that we may both give and receive such beautiful things as ideas, openness, dignity, joy, healing, and inclusion." -Max De Pree

This FIFTH EDITION of the New Parent Guide has been prepared by the Northwest Down Syndrome Association (NWDSA). We are pleased to be able to provide this resource to new parents, as well as to friends, families and medical professionals. Our goal is to provide useful information about Down syndrome and most importantly to share the joys, challenges, and experiences of raising a child with Down syndrome.

There are many books published about Down syndrome, and our goal was to compile and edit thoughtful, helpful information from a variety of sources. We have included photos of our children and families because we want to share with you our sons and daughters—to show you living examples of hope, love and happiness. Just like you, we were at one time brand new parents of a child with Down syndrome. We share our families and experiences with you because we share your journey. Some day you may want to do the same for other new families touched by Down syndrome.

NWDSA

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NWDSA is a program of NW Disability Support