

Welcoming a Newborn with Down Syndrome: A New Parent's Guide

Second Edition

Nancy McCrea Iannone and Stephanie Hall Meredith



DownSyndromePregnancy.org

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By Nancy McCrea Iannone and Stephanie Hall Meredith

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Audience

This book is meant to be a resource for new parents learning that their newborn has a diagnosis of Down syndrome. It is not intended for expectant parents learning about a prenatal diagnosis. Instead, expectant parents should seek information from our companion book, "Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome" at downsyndromepregnancy.org for those preparing for the birth of a baby with Down syndrome. "Understanding a Down Syndrome Diagnosis" at lettercase.org is also available for those first receiving a diagnosis or screening results.

A Note to Down Syndrome Organizations

As you support new parents, we recommend you provide them with a link to DownSyndromePregnancy.org where they can access online articles, the digital book with active links, and quality printed copies available for purchase in English and Spanish.

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WELCOME



Dear New Parents,

First, congratulations on the birth of your new baby! Even though you might feel overwhelmed after learning your newborn has Down syndrome, this new addition to your family will have their own individual personality with strengths and challenges you will discover along your journey.

Parents sometimes feel emotional and confused in the beginning. You may feel scared if your child has been whisked away to intensive care for tests; you may adore the little bundle folding into your chest; and you may also feel alone and unsure of where to turn with your questions.

This book was written to help you cope with the newborn stage and give you hope for a meaningful future that may be difficult to picture right now. You are not alone, and parents all over the world are ready and willing to share their experiences, knowledge, and support. Many parents are available to provide a helping hand in person, over the phone, or online, and this book is a compilation of advice from professionals and parents of children with Down syndrome.

Your situation is unique and individual, and no one can ever truly understand how you feel. However, we can share what we have learned to help you along your journey.

Most parents find that the initial moment of learning about the diagnosis is stark and crystal clear, but the days and weeks afterwards are hazy, confusing, and often overwhelming. But, after we emerge from that cloud and live with our babies, we can't imagine our lives any other way. We then develop an appreciation for their unique gifts, talents, and beauty. Now we fiercely love our children, feel a deeper appreciation for humanity and empathy towards others, and realize that life with Down syndrome is more work but also is remarkably ordinary.

Warm Regards,

Nancy Iannone and Stephanie Meredith

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EXPLAINING THE BASICS

Many new parents start this journey with some basic questions: What is Down syndrome? What is life like for people with Down syndrome and their families? What possible health issues should I learn more about, and where can I get more help? Once parents have a basic understanding, they are usually eager for more detailed information. This chapter explains those basics, and how to use this book to learn more.

UNDERSTANDING THE BASICS ABOUT DOWN SYNDROME

Down syndrome is a genetic condition that is usually caused by an extra copy of the twenty-first chromosome. About 214,000 people in the US have Down syndrome, and studies show that about 1 in 770 babies is born with Down syndrome.¹ The chances of having a baby with a genetic condition increase with the mother's age even though parents of all ages have children with Down syndrome.

1 <https://dsuri.net/us-population-factsheet>

The medical conditions and abilities vary widely for people with Down syndrome; however, they generally have mild to moderate cognitive delays, low muscle tone, and a higher risk for a variety of health issues, particularly heart defects.

Over the past few decades, the outlook for people with Down syndrome has improved significantly thanks to advances in health care, education, and public attitudes.

Healthcare has improved drastically over time. The average life expectancy for people with Down syndrome has actually increased from about 20 years-old in 1970 to about 60 years today.^{2,3}

People with Down syndrome have also benefitted from various education programs. States provide Early Intervention services to children before age three. In addition, individual education programs in public schools, ranging from inclusion in the typical classroom to small group classrooms, create better learning atmospheres. After high school, over 260 college programs for people with intellectual disabilities offer more opportunities for independence and growth.

Improved public attitudes and acceptance have also meant that many people with Down syndrome are thriving as active and valued members of the community. This includes children who are increasingly joining social and school programs with their peers, and many adults who are employed and live independently or with some support.

As you try to grapple with questions about what a Down syndrome diagnosis means for your child, remember that this baby is first and foremost a member of your family. Your child will have his or her own individual personality, interests, strengths, and challenges that are partly influenced by that extra chromosome—and also influenced by your genetics and environment in your home.

2 Glasson, E.J., Sullivan, S.G., Petterson, B.A., Montgomery, P.D., Bittles, A.H. (2002). The changing survival profile of people with Down syndrome: implications for genetic counselling. *Clinical Genetics*, 62:390-393.

3 Wu J., Morris J.K. The population prevalence of Down's syndrome in England and Wales in 2011. (2013). *Eur J Hum Genet*; 21:1016-1019.

USING THIS BOOK

This book gives parents of newborns with Down syndrome essential information you need to know after your child is born. Please know you will not necessarily encounter every single point we discuss in this book because your child will not be exactly like any other child with Down syndrome. Our goal is to provide the tools and information you will find most useful in the beginning. If any information is unduly concerning, you can jump to another section that pertains more specifically to your experience.

The DownSyndromePregnancy.org website features other helpful books, including “Breastfeeding and Down Syndrome” and “Your Loved One Is Having a Baby with Down Syndrome” for family and friends to better understand your experience and how to provide support. The website also features articles and downloadable resources that correspond with the book chapters. These articles include links to additional resources and parent stories, and we also add updated information in these articles to let you know about anything new.



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ADJUSTING TO A DOWN SYNDROME DIAGNOSIS

The personalities and life experiences of parents receiving a diagnosis of Down syndrome are quite different, but the journey can feel remarkably similar. Most parents say that it is an emotional roller coaster. The hardest moments are usually at the time of diagnosis and right afterward, which are commonly followed by emotional growth and bonding with the baby. This process is both expected and very normal. Parents often find their grief begins to dissolve as their concerns are addressed, and they embrace their child as an individual instead of seeing them only through the lens of a diagnosis.

RECEIVING THE NEWS

Many parents report that the most difficult part of being the parent of a child with Down syndrome is receiving the news about the diagnosis and coping with the emotions afterward. Often, the moment of diagnosis is described as a

“flashbulb memory”⁴—one that new parents remember with perfect clarity for many years. Some new parents say it feels like “time stopped.”

Most parents feel overwhelmed after learning that their baby has Down syndrome, especially when the diagnosis is unexpected at birth. Many new parents feel some level of sadness or grief though the intensity varies among parents. While some parents accept the diagnosis right away, many parents describe grieving the “typical” child they thought they would have. The grief might also be related to fears about how others will treat their child, worries about how to get help and support, concerns about health issues or adulthood, or deep social biases about disability that they never considered before.

That moment is often shaped by the way the diagnosis was delivered, the support network available, the resources received, and prior experience with people who have disabilities. The way you react may depend on many different factors. Did you receive support and information right away? Was your pediatrician/obstetrician helpful? Were your family and friends supportive? Do you have friends or family with disabilities who help you understand better? Are there other hardships in your life right now? Are you dealing with other medical conditions affecting your baby, such as a heart issue?

Many circumstances influence how parents feel when they receive the diagnosis, and it’s also normal to feel guilty for being shocked or upset. However, most parents find these strong feelings fade fairly quickly as they are patient with themselves, find information and support, recognize that they are not alone, and get to know their baby.

Some suggestions for adjusting to the news:

1. Write down all of your concerns and discuss them one by one with someone you trust and who can help you find the answers. This could be your partner, your family or friends, your pediatrician, support volunteers at a local Down syndrome organization, or anyone you think would be understanding.
2. If you are feeling sad in the moment, don’t beat yourself up. Recognize that it’s normal, and read the stories of other families whose babies were born with Down syndrome, like Kelle Hampton and the authors in *Gifts*.

4 Skotko, B. (2005). Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics & Gynecology*, 192: 670-677.

From Kelle Hampton, writing about her initial reaction in her blog “Enjoying the Small Things”:

I suppose it's horrible to say you spent the first night your daughter was born in that state of agony, but I know it was necessary for me to move on to where I am today. And, knowing where I am today and how much I love this soul, how much I know she was meant for me and I am meant for her, knowing the crazy way our souls have intertwined and grown into each other, I can say all this now. It's hard, but it's real, and we all have feelings. We live them, we breathe them, we go through them and soon they dissolve into new feelings. So, here I go.

I cried out that I wanted to leave her and run away. I wanted to take Lainey and my perfect world and this perfect love I had built with my two-year-old and our cupcake-baking days and our art projects and our beautiful bond and I wanted to run like hell. I wanted to be pregnant again. I wanted to be pregnant so bad. I wanted it to be the morning she was born again...when I was happy and excited and when I wore the white ruffled skirt and black shirt and put it in the belongings bag knowing joy was to come. I wanted to go back...

I moaned in pain and through it all, this little breath of heaven needed me. I cried while I nursed her. I cried while I held her. I cried while I pulled my nightgown off just so I could lie her body on my naked skin and pray that I felt a bond. I literally writhed in emotional pain for hours...

...and then morning came. ...and with it, hope.

3. Do all the things that make new moms excited about their babies: fill out the baby book, take newborn pictures, make a music playlist for baby, and create birth announcements. Enjoy those precious moments when your baby is very tiny.
4. Take the time to compose yourself before telling other people so that you are more likely to get the reaction you want from them. If you sound sad, other people will probably match your sadness, but if you sound excited, other people will usually respond with excitement. And sometimes people will surprise you in the best possible ways.

From Amy Geoffroy, writing about how she told friends and family:

I tried to be forthright with the information about our daughter's diagnosis and radiate a sense of calmness and positivity, hoping it would rub off on people. That was really hard at the time and took a lot of emotional energy which I couldn't

spare. Still, most people stopped telling me they were sorry when they realized I wasn't going to indulge their own sense of morbidity.

From Steven, describing the reaction from his best friend:

When I called my best friend and choked up when telling him my son was born with Down syndrome, his response was, "So what." I was surprised by his reaction until he explained, "My cousin has Down syndrome, and she's great. Your baby's going to be just fine." This was exactly the response I needed at the time to shake me out of feeling sad.

5. Try to gain perspective that while you may be shocked and overwhelmed right now, those emotions are usually temporary. Most parents look back and wish they hadn't been so worried.

From Missy Skavlem, writing about what she wishes she could say to her past self:

You worry she will be a burden. You are wrong. She is going to be funny, fun, and a joy.

You think this will be difficult for the other two kids. You are wrong. They will be better, more compassionate people because of her. She will be their sister—they will fight and make-up just like the other girls. She will also unify them—they both have a favorite sister, and she is their favorite.

You think having a child with Down syndrome will ruin your marriage. You are wrong. You married him for a reason—he will not miss a step in loving her, and he will never see any meaningful differences in her.

You think you might not be able to handle this, that moms of kids with Down syndrome are "special" themselves somehow in a way you aren't. You are wrong. You have what you need, and those moms aren't "super moms" either.

You think you might have to quit your job and totally change your life. You are wrong. Your life will be pretty much the same—busier and harder that first year, but you'll adjust just fine to your new normal.

You think maybe it would be better if you miscarried her—then you think you are a terrible mother for thinking that. You are wrong. That would not be better. And you aren't a terrible mother, just ignorant and really, really, really afraid. Forgive yourself and move on.

You think you are all alone. You are wrong. You will have more friends and more Down syndrome family than you ever imagined. And they will be amazing!

You think having a child with an intellectual disability will be terribly hard for you to adjust to and that seeing her struggle will make you sad. You are wrong. You will learn that the value and worth of a child is much richer and deeper than that, and that sometimes what is being measured isn't the most important thing. She will inspire you with her strength.

You think you will never stop crying. You are wrong. Every tear you shed will be rewarded with 30 laughs that she inspires—on purpose—within the first two years.

SWIRLING EMOTIONS

In addition to the often-overwhelming experience of diagnosis, the time immediately afterward may be difficult. Sometimes parents' sadness is tinged with guilt about having negative thoughts about their child. Parents may also be in denial about the diagnosis while waiting for the genetic test results and then feel guilty for hoping the initial diagnosis at the hospital was wrong.

Some parents may blame themselves or their partner for their child's condition. Please realize there is nothing you or your partner did to cause your baby to have Down syndrome.

As you wade through this swirling river of emotions, let the feelings flow. It usually helps to find someone who is supportive and understanding to stay by your side and listen without judgment. These strong feelings and concerns are often a natural part of the adjustment process, and it is normal to feel vulnerable, sad, angry, or isolated. Most parents say the intensity of these emotions fades quickly as they get to know their baby.

While experiences are similar, some variation exists in terms of emotional recovery time and specific thoughts or fears. Many of your life experiences, especially whether you have known people with Down syndrome, will influence your emotional healing. Some of the many emotions parents have experienced are:

- Fearing the ability to bond with the baby, especially if the baby is whisked away to the Newborn Intensive Care Unit (NICU)
- Feeling intensely overprotective of the baby
- Fearing that either you or the baby will be defined by a diagnosis
- Fleeting thoughts that it would have been better not to have this baby and then shame for thinking that

-
- Blaming yourself (“Was it something I did?” No, it wasn’t.)
 - Feeling inadequate to the task of raising a child with unique needs
 - Frustration that other people treat you like an object of pity or admiration
 - Frustration that you aren’t getting enough sympathy when you want it
 - Feeling alone, like no one else understands
 - Intense concern over medical issues and feeding, especially if your baby is in the NICU or if your baby has a heart or gastrointestinal condition
 - Thoughts of “Why me? Why us? Why my baby?”
 - Topics or words that previously flew under your radar are now sources of emotional pain, such as slang words for those with intellectual disabilities

These feelings are common for many new parents and do not reflect how you will be as a parent or how you will bond with your baby. They are a normal part of the adjustment process, and it is important for you to allow yourself to experience these emotions and to forgive yourself for any painful thoughts once you have moved forward.

Family Stories

From Jennifer Enderlin, talking about her experience coming to terms with her son’s diagnosis:

It took me a long time to come to a place of acceptance.

Why am I telling you this? I’m telling you this because I am no longer in a place of acceptance. I am in a place of such utter love and breathtaking happiness that my son is mine.

I took this hard. So hard that I felt like I had been hit by a Mack truck and dragged down the concrete with my face being scraped every step of the way. I was the last person I thought could handle being a “special needs mother.”

And all I can say now is that I promise you, you will find peace. You will find more than peace. You will find more than joy. You are so, so, so lucky. And it’s so hard to see right now.

Don’t try to rush to this place of peace. The more you try to “get there” the longer it takes. The only way out of grief is through it. You have to feel it. You have to cry. You have to get pissed off. But do all this with a hopeful heart. The love for your child just comes, whether you want it to or not.

I was constantly watching for the day I would fall in love with my son. And you know what? It snuck up on me without me even being aware of it. One day I was holding him in his room, he was sleeping on me, and the feeling of love washed over me so hard I bit my lip. But please know this did not come early for me.

Remember a couple of other things, too: right now you may feel very angry, though it won't feel like anger. You can be so pissed at other people: pissed if they give you pity; pissed if they don't seem to give you pity. No one will be able to do anything right in your eyes. This is so normal. Try as hard as you can to laugh about it.

And then, get ready for the biggest, most thrilling roller coaster of your life.

Worrying about Medical Issues

In the midst of adjusting to a Down syndrome diagnosis, some parents must also deal with the immediate medical needs of their children, particularly those with heart or gastrointestinal conditions. Many parents describe Down syndrome as secondary to the more pressing health conditions their child is facing. Some even say they perceive their child much more as a “child with a heart defect” rather than a “child with Down syndrome.” If your baby is dealing with pressing medical issues, you might want to “put Down syndrome on the back-burner” to cope with the immediate needs at hand. You have plenty of time to adjust in layers, so do not feel guilty if you need time to process each diagnosis. You may also want to reach out to your local support group or online groups to find parents whose children have similar conditions.

CELEBRATING YOUR BABY

Fortunately, the adjustment phase usually passes fairly quickly as parents fall in love with the baby in their arms and as the baby's personality emerges. Even though it may be difficult to accept a diagnosis at first, most parents feel joy as they get to know their baby. The diagnosis becomes just one part of a captivating little person with sweet-smelling hair, soft skin, and tiny fingers. Parents usually become eager to celebrate their new little one, and life with a baby who has Down syndrome turns out to be pretty similar to life with any newborn, including lots of diaper changes and midnight feedings. The primary differences are that some little ones with Down syndrome might have other health issues that are usually treatable in the first year, and they might have difficulty feeding. Beyond that, babies with Down syndrome are mostly the same as other

babies—though some families say their baby with Down syndrome is their easiest child.

Parents often feel most excited as they actively start to embrace the newborn phase—calling friends and family, taking naps together, and figuring out baby's favorite feeding position.

Family Stories

From Stephanie Meredith, talking about loving Andy:

During the first few weeks, I worried incessantly about getting out of the NICU, monitoring feedings, and trying to figure out what the future would hold. It was a rough few weeks, and there were moments when I wondered if I'd ever feel happy again. My first glimpse of joy was when I staged a photo shoot in our living room when Andy was about 3 or 4 weeks old. He was just so cute, expressive, and vulnerable at the same time, and I truly started to see him for the first time through the lens of that camera. Then, as I read "The Chronicles of Narnia" to him during feedings, I began to feel relaxed and peaceful as he stared up at me and I rubbed my lips against his hair. It was in these moments that I realized he was mine, and I loved him utterly and completely. For me, it wasn't a sudden wave of emotions but rather a warm blanket slowly wrapped around both of us.

EXPLORING QUESTIONS ABOUT FAITH AND DOWN SYNDROME

By Bill Gaventa, M.Div., Director, *Summer Institute on Theology and Disability*; Editor, *Gleanings*:

For people of faith, any of the feelings and issues that you have as a new parent can get magnified and intensified by questions of faith, meaning, and the role of God, however that is defined in your own faith tradition. The "Why me?" question is a universal part of responding to something that is unexpected, a natural part of figuring out what something as powerful as the birth of your child means for you, your family, and your child. It can be expressed as anger, at God and others, or, when towards oneself, often is felt as guilt.

Be wary of quick answers. Any question or feeling is appropriate and can be shared and/or prayed about in the context of one's faith. In many faith traditions, parents of children with Down syndrome have often too quickly felt or

heard things like “You have been chosen” or “Your child is an angel from God” on the one hand, or, at the other, “What did you do wrong?” or “If you pray hard enough, he/she can be healed.” Learn your own responses to those kinds of quick answers. Don’t rush to figure this out. Faith is ultimately a relationship, one in which you can come to your own understanding of meaning with the help of your tradition and faith community.

Often, over time, families whose faith is important to them often center their relationship with their new child as they do on other children: i.e., my child is a gift, uniquely made in the image of God (however your tradition defines the divine), a gift to love and one who will love them. Increasingly, families are finding their faith leaders and communities walking with them in that journey. Your child can be a blessing one day and challenging the next, like any other. There are multiple ways that faith and faith communities can help. (Don’t hesitate to ask. People who care often love having something to do.) Sometimes it may be with specific tasks, others with simply listening, welcoming, and including your child and family from the day of his or her birth.

The numbers of resources related to faith, families, disabilities, and congregations are growing by leaps and bounds. If your own clergy or faith community do not know about them, check with the national offices, and/or get on the internet and type in “faith,” “disability,” and “inclusive ministries.” Other parents have written stories about their faith journeys with their child. Respite care, advocacy, emotional and spiritual support, and being in a community where your child can be loved, celebrated, and contribute to others are all possibilities. In doing so, everyone’s faith has the opportunity to grow along with your child and your family.

Family Stories

From Amy Julia Becker, talking about her Christian faith and the questions she asked about her daughter’s diagnosis:

When Penny was born, I had so many questions for God, ranging from whether or not He would take care of her to whether or not I was fit to be her parent. Over time, the fearful questions faded because I began to believe that Penny truly was a gift to us and to the world around us. Now that she’s older, she has her own questions for God. I’m trying to teach her that no questions are off limits, even if they don’t all get answered. More than anything, I’m teaching her what she helped me to learn, that at our core, we are all deeply loved by our creator.

From Melissa Kline Skavlem, describing the role of her Catholic faith and how she came to understand her daughter's diagnosis of Down syndrome:

As the mother of Violette, I have often thought about Mary, who was called by God to be the mother of Jesus. I had a very hard time right after Violette's birth adjusting to the idea that it was God's will that I would parent a child with Down syndrome. I was so scared of what it meant to my family and what that would look like in my life? At the time, I didn't fully realize the extensive gifts that were going to come to me and my family. In many ways, the diagnosis was initially a challenge to my faith, but time and perspective helped me recognize that God's plan and will were perfect for all of us.

Violette's First Communion was this spring. The woman who offered her Eucharist for the first time came to me in joyful tears after the Mass, saying what an honor it was to share that sacrament with Violette for the first time. Down syndrome may be the background of the mosaic that is her life, but for her family and friends, she is much more than her diagnosis. My girl is a light in my life and brings great joy to me. I know that my initial feelings at her diagnosis were based on fear, and I have forgiven myself for not having the willingness of spirit that Mary showed us in her example right away. Now, I sometimes sit in Mass with my arm around Violette and wonder, "Do the other parishioners feel sorry for me and her and us?" I usually smile, and think how ironic that would be; because I feel sorry for them that they don't know what a privilege it is to parent my lovely girl.

From Mitchell Levitz, describing his commitment to faith and tradition as a Jewish man with Down syndrome:

I believe that my views about my religion and heritage are an important part of my life. When I go to services and read the prayers, I believe what they tell me. The values of religion, faith, and heritage were taught to me by my family and other important people who I cared about. These views about religion were of major importance to me. I believe it was a part of my life to be religious and to believe what I felt when I was Bar Mitzvahed. I was capable to read and chant this Hebrew language. It was a very special part of my life to fill the dream that my father had that he saw his son become an adult. Tradition is very important to me because I feel that I want to follow in my family tradition steps...⁵

5 Excerpted with permission from *Count Us In: Growing Up with Down Syndrome*. Afterword. A book by Jason Kingsley and Mitchell Levitz (1994). Re-release with new Afterword. Harvest Book, Harcourt, Inc., Orlando. (2007, March).

LINGERING FEELINGS

As you move forward after the birth of your baby, you will likely move away from the very intense emotions, growing into acceptance, hope, and peace. However, this growth often comes with mixed emotions that can be influenced by positive or negative news at medical appointments, helpful or hurtful comments by those around you, or specific events in your life.

Embracing life with your new baby may result in days, weeks, or months of peace. However, certain events may trigger unexpected moments of sadness or grief, where you start to feel overwhelmed again. Those triggers could be:

- Your baby is not eating properly.
- You are preparing for heart or GI surgery.
- Breastfeeding is not going as planned.
- Recovery from surgery is taking longer than expected.
- Someone says something hurtful or inconsiderate.
- You learn your child has another health issue.
- You see a baby the same age as your baby who is further along developmentally.

Moments of sadness or frustration are normal even after you have completely accepted the diagnosis and fallen in love with your baby. Be patient with yourself and find the support you need by writing in a journal, talking to loved ones, taking time for yourself, reaching out to local or online support groups, or whatever helps you recover.

Interaction with other parents may simultaneously reassure you and leave you thinking you are somehow different. “They seem to be fine emotionally, so what’s wrong with me?” Most likely, if you specifically ask these parents about their emotions post-diagnosis, you will hear repeated stories similar to your own. These parents are usually not much different from you; they are just further along on the journey.

Everyone has setbacks from time to time, but once you get past any first year health issues and get to know your child as an individual, you can quickly get back on your feet.

LOOKING FORWARD

Research also shows that most people with Down syndrome are overwhelmingly valued and loved by their families. So, even though your emotions may swing after the birth of your baby, most families adapt and find joy. Interestingly, the results of this research on families did not change based on the abilities of the individuals with Down syndrome — meaning that satisfaction in family relationships did not depend on whether individuals had significant or mild disabilities.

- 99% of respondents with Down syndrome said they are happy with their lives, and 97% of respondents with Down syndrome reported they liked who they are⁶
- 99% of parents said they love their child with Down syndrome⁷
- 97% of brothers/sisters, ages 9-11, said they love their sibling⁸

Studies show that most families of children with Down syndrome are resilient and ordinary. They go on family vacations, referee sibling squabbles, play, attend work and school, and eat out just like everyone else. Sometimes they just have to figure out extra health issues, doctor appointments, therapy visits, and services, but most families appreciate their loved one with Down syndrome and go through their daily routines like everyone else.

Related Articles on DownSyndromePregnancy.org

You can visit DownSyndromePregnancy.org for articles such as, *"The Emotional Impact of Diagnosis," "Reclaiming Joy," "Diagnosis Day: Parents, What Would You Say to Your Past Self?," "Who Was I Then? Who Am I Now?," "25 Things I Wish They'd Told Me in the Hospital When My Son Was Diagnosed with Down Syndrome," "50 Things to Do Instead of Worry," and "Support for Dads."*

6 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Self-perceptions from people with Down syndrome. *American Journal of Medical Genetics, Part A*, 155:2360-2369.

7 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Having a son or daughter with Down syndrome: Perspectives from mothers and fathers. *American Journal of Medical Genetics, Part A*, 155:2335-2347.

8 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Having a brother or sister with Down syndrome: Perspectives from siblings. *American Journal of Medical Genetics, Part A*, 155:2348-2359.

GETTING PROFESSIONAL COUNSELING

Giving birth is exhausting, and the additional impact of adjusting to a diagnosis and dealing with possible health issues can be particularly difficult for some families. You need to take care of your own emotional well-being, especially if there are other stressful events in your life or a history of mental health issues. Seeking the assistance of a therapist may be a necessary step for some families, and can help you care for your child on more solid emotional ground. Do not hesitate to ask your medical care provider for a referral to a counselor if you need someone who will talk with you about your fears, concerns, and stress.

Giving birth with complications can put any new mom at risk for depression, especially if other factors are present, such as previous history with depression or other life circumstances. Many variables are considered to see if a mom is at risk for or is currently feeling depressed. A useful self-check list is [The Edinburgh Postnatal Depression Scale \(EPDS\)](#). You may answer “yes” to many of the questions involving sadness, fear, or stress, because these are common feelings after a diagnosis. For many new parents, family support, local Down syndrome groups, or online communities may provide appropriate emotional support. For other families, an appointment with a psychologist may be needed.

To find professional help, contact your doctor for a referral to therapists in your area. You can also contact [Postpartum Support International](#) (1-800-944-4PPD) to identify a local therapist. When you reach out, request a therapist trained in “unexpected outcomes.”

Even when professional help is needed, sometimes this is impossible for families who are limited by time constraints or geography. [Postpartum Progress](#) has online support, including tools and advice for self-help and family support, as well as a monitored discussion board.

If you experience suicidal thoughts, you should immediately see a therapist, go to the Emergency Room, or contact [The National Suicide Prevention Lifeline](#) (1-800-273-TALK (8255)).

Based on an interview with:

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SHARING THE NEWS WITH FAMILY AND FRIENDS

Our loved ones have so many questions: “How much did the baby weigh? How was the birth? Is the baby a boy or a girl? What’s the baby’s name? How long will you be in the hospital? Is the baby healthy?” Grandparents, aunts and uncles, our co-workers, and the neighbors next door all want to know details about our new baby. They care about us. But what if you’ve received news that your child will not be the “typical” child you planned? What if you’re emotional and can’t deal with the questions? They’re still going to ask and look to you for the answers, even though you may feel completely unprepared. Developing a plan for sharing the news can help you manage the tone of your own story. That way you are more likely to get helpful reactions and support from your loved ones.

WHOM TO TELL?

There are a variety of approaches by parents of children with Down syndrome. Some parents tell everyone they know, even strangers who ask about the baby. Other people only tell those who are close to them and don’t feel the need to share the diagnosis with strangers. Sometimes immediately after birth, new parents want to be surrounded only by those who are the most supportive.

We suggest you make a deliberate choice about whom to tell right away. Some questions you and your partner may ask yourselves are:

- Do I have supportive family members who will be helpful immediately?
- Do I have intrusive family members who will annoy me with advice and questions?
- Does my family have an outdated view of Down syndrome?
- Have any of my family members dealt positively or negatively with disabilities in the past?
- Does my family have experience with people with Down syndrome? Will they be able to help with insight?
- Will telling people outside my inner circle make me uncomfortable?
- Am I afraid of social awkwardness or always having an “elephant in the room”?
- Will keeping it to myself make me feel like I am ashamed?
- Do I gain strength and comfort from talking things out with friends or family?

Considering these questions allows you to develop a strategy and make a purposeful choice about whom you will approach for support and understanding during the first few days and weeks. Of course, it’s important to realize our loved ones may react differently than we expect. You might find comfort in remembering they too are adjusting to unexpected news.

WHAT TO TELL?

What do you say to these people you depend on for love, support, and guidance? We suggest that you be honest about the unexpected news, your emotional state, the fact that you are learning, and your hope for the future. Sometimes friends and family are quick to jump to the “sorry space” and may say things that are unintentionally hurtful. Therefore, many parents want to make an announcement to set the tone and shape the narrative. This strategy can help new parents get the response and support they want from their loved ones. The announcement can also include recommendations to help their loved ones learn more about Down syndrome through websites, videos, books, or local Down syndrome organizations. When loved ones occupy their time learning, they are also more likely to provide the support you need. Here are some ideas for that announcement broken down in parts:

Introduction: Hello to friends and family (or coworkers, neighbors, employees).

Reminder: As many of you know, our baby was born yesterday, and we have named him/her NAME. We are so very excited about this addition to our family.

Details: (Add any personalized details you want to share such as birth weight, hair color, and length.)

Diagnosis Feelings: We have recently learned that our sweet baby has Down syndrome (and whatever other issues if any). We are excited about our baby, but we're also still adjusting to unexpected news. If you see us, we may still be emotional, but we have learned from other parents that we will move away from this time of uncertainty to a place of excitement and amazement. One thing we know for sure: we love our baby, and we hope you will join us in welcoming him/her.

Learning: We know that you must have many questions, and we will try our best to answer, but we have a lot to learn ourselves. We have already started to research, and you can look at DownSyndromePregnancy.org for some basic information for friends and family in the booklet, "Your Loved One is Having a Baby with Down Syndrome." Some of the most important things we have learned are that each person with Down syndrome is a unique individual, and that recent advances in medicine, education, and acceptance have greatly improved outcomes. More importantly, we have learned that our child will live a rich and rewarding life, and will enrich ours as well.

What to say to us: We know many of you may not know what to say to us when you see us—and we understand. We're not sure we would have known what to say either. Please tell us congratulations, tell us how cute our baby is, and make an effort to learn about Down syndrome. We would appreciate if you could avoid saying, "I'm sorry." Even though we are adjusting to the diagnosis, it's not something to be sorry about because we're very happy about our baby. You can also find more suggestions for supporting us in "Your Loved One is Having a Baby with Down Syndrome" at DownSyndromePregnancy.org.

Closing: Thank you all so much for your love for us and for welcoming our little one. The opportunities for people with Down syndrome are better than ever, and we're looking forward to the bright future ahead for NAME.

The ideas above give you a generic outline for telling people the news. Of course, your approach will depend on your personal circumstances and comfort level. Bottom line: speak from the heart. Many people will follow your lead.

WHEN TO TELL?

Most new parents who receive a postnatal diagnosis find out their new baby has symptoms of Down syndrome within the first day or so. They usually have already announced to friends and family that they are packing their bags and heading to the hospital for the birth, and those loved ones are eagerly awaiting the news.

Some new parents go home right away and are eager to tell everyone about their baby, including the diagnosis. On the other hand, some parents need a short delay to process the information before sharing the news with friends and family. Most people anticipate that the first days after a baby is born are chaotic—whether a baby has Down syndrome or not—so they usually understand.

Sometimes delivery complications or unexpected health issues leave new parents unable to focus on anything or anyone except their new baby during the first few days and weeks. So, you may choose to share the news after your baby overcomes the most pressing medical issues. New moms might also need a little extra time if they are coping with postpartum depression.

Many parents of newborns with Down syndrome tell their loved ones about the diagnosis in phases. They may want to tell the most supportive and understanding people in their lives during the first few days as they absorb what the diagnosis means and overcome any shock. Often, those who are closest to the new parents are in the hospital room or recovery room. Then, parents usually share the news more broadly once they have more information about Down syndrome or have processed any difficult emotional adjustments.

Because you may not be able to control your emotions right away, a short delay in telling your loved ones about the diagnosis can give you the benefit of being able to gather your thoughts, rein in your emotions, and deliver the news from a position of relative strength. Taking as much time as you need may make it easier for you to craft your message with the right tone and level of information.

HOW TO TELL?

These days your options for how to tell people the news are limitless: in person, phone call, email, social media, let the word spread. You may find that informing the people you know usually involves multiple methods.

Telling your closest loved ones in person may be an option if they live close to you and plan on visiting right away, but be prepared for a potential surge of emotion when you see their reaction. Telling the news in person also allows your family and friends to enjoy seeing that beautiful new baby so that the diagnosis is just a part of a wonderful new arrival.

Phone calls or video conferencing allow you to tell those closest to you one on one, and give you an escape hatch if the conversation becomes overwhelming. Phone contact also allows you to reach close relatives who live far away. However, it may be difficult to speak coherently if you are emotional.

Both in-person and phone contact create an opportunity for loved ones to comfort and congratulate you in real time, but these methods may leave you vulnerable to the unpredictability of the immediate reactions of others. People reacting to unexpected news can sometimes do or say something unintentionally hurtful.

Sometimes you can tell a select group of people and ask that they pass on the news. This allows others to react away from you and compose themselves before talking to you. It also saves you from the potentially uncomfortable task of telling. It can also make you feel like people are talking about you, and others may pass on misinformation, so be aware of these possibilities. You may also be unaware about who does or does not know, which may lead to some awkward situations in the future.

A group email or text will allow you to craft the message and convey the tone you want, and may avoid a one-on-one emotional meeting. A group message can be forwarded easily so your message will stay intact. It may not be ideal for your closest loved ones, but it is a good tool for informing a large group of people.

Large social networks, such as Facebook, Instagram, blogs, and Twitter, are also a popular way of sharing updates with family and friends. It may be useful to share the news about your baby on these sites when you want to reach a large

group of people at one time or reach people whose contact information is difficult to find. This is often the preferred method when you are ready to let everyone know.

Social media allows you to control the message, but, unlike email or text messages, it also leaves you open to immediate and public reactions from others who could be wonderful or, occasionally, thoughtless. For this reason, most new parents find social media to be a better second or third tier method of making an announcement, after they have already told close friends and family and have had time to adjust to the diagnosis.

Fortunately, our social media friends usually follow our cues. So, if you share the diagnosis with a positive perspective, then most comments will likely reflect your tone and be a genuine source of strength and support.

However, if you have a person in your circle who has a history of causing drama on social media, you may wish to use language in your post that establishes boundaries about the way in which your announcement is shared, or you can be more specific about the kind of support you want. You may also want to monitor your privacy settings based on your preferences.

Note that if you post photos and don't acknowledge the diagnosis, it is possible that some friends and family may notice the characteristics of Down syndrome and feel awkward approaching you with questions.

You can also send crafted print or digital birth announcements with a picture of your baby, the vital statistics, and an acknowledgment of the diagnosis in an accompanying letter. That way people will be given the opportunity to understand and also recognize that you are celebrating the birth of your beautiful baby.

BEYOND SHARING THE NEWS

After you share the news, your friends and family may have many questions and comments about the diagnosis.

For a basic description of Down syndrome and suggestions for your loved ones about how to support you, please see [*"Your Loved One is Having a Baby with Down Syndrome"*](#) on the Down syndrome pregnancy website.

Family Stories

It was of the utmost importance to me that everyone viewed Graham's arrival positively. It was initially hard for my husband, because this meant that I wanted to wait a short amount of time to share the information very deliberately and positively. We told our immediate family in person, but mailed Christmas cards to all of our close friends and family with the news. I simply didn't want to have to remember who I had told nor deal with watching them process their emotions regarding his diagnosis. —Sabrina

I told everyone via e-mail! I wanted to control the message, didn't want anyone gossiping, and didn't want any "I'm sorry." I did pretty well – I only had one person say I'm sorry to me, and she hadn't gotten my e-mail. I think it is better to send to more people than you think you need to. At first it wore me out to tell people. —Missy

I made my best friend do it. Seriously. —Megan

Related Articles on DownSyndromePregnancy.org

You can visit DownSyndromePregnancy.org for articles such as, [“Sharing the News”](#) and [“Positive Support from Family and Friends: Saying Thank You.”](#)

Both articles include templates for emails and social media posts that you can copy, paste, and personalize to tell the news to friends and family and express thanks. Even though these templates were written for expectant parents, they can be easily modified for new parents.



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DEALING WITH COMMENTS

After you start telling people about your baby's diagnosis, you will hear comments that give you strength and support and help you cope with your new reality. Most friends and family are very welcoming and kind, and then there are those who say just the right thing at the right moment. New parents usually appreciate friends and family the most who listen compassionately to their concerns, congratulate them on the birth of their baby, strive to learn more about Down syndrome, and talk about the baby as an individual.

However, other comments might make you uncomfortable. Of course, new parents react in a variety of ways. You may not be sensitive to comments at all, or perhaps you have never been sensitive, but you feel more fragile after the birth of your baby. This section aims to give you informative ways to respond, while knowing that your initial emotional reaction is understandable and often justified.

Our approach is simple: plan for the comments and create an informative, collected response—your “crafted response.” The reason we do this is because a crafted response can often help you control the tone of a conversation and educate the other person so that you are more likely to get a supportive response. But recognize that your gut-reaction to these comments is also natural and may

be something you want to say to someone else or write about in your journal—your “unfiltered response.”

Remember that the majority of people do not mean to hurt you. Most people are kind-hearted and only wish to support you. However, they just don’t know how their comments sound or are unaware of the emotional turmoil you may be experiencing. Often the speaker has no idea that this is the 100th time you’ve heard their question or reaction. While many new parents have been tongue-tied from surprise and anxiety by some comments, hopefully, you will be prepared.

As you read these suggestions, please do not feel that you must respond any certain way, especially when your emotions are raw. We agree that if there is any time in your life that your loved ones should be “walking on eggshells” around you, this is the time. It’s entirely up to you to choose what you want to say and how you want to say it. However, some parents feel more confident when they craft their messages beforehand with an educational tone. Others prefer to be candid in their responses and share more of their feelings. The key is to consider who you are talking to and what you want to say so that you receive the support you want—or as close as possible.

APOLOGY COMMENTS

Your friends and family usually want to empathize when they perceive that you have received “difficult news.” This is especially true if they have no experience with Down syndrome and may think it’s a condition that can be harmful to your baby or curable. If your baby is in the NICU or has a heart condition, your friends and family may also feel sad that your baby has a health issue. In these cases, you may appreciate their compassion and empathy.

Unfortunately, if they make comments like, “I’m sorry—this must be tough,” you might feel like they are sorry your baby was born with Down syndrome. While some new parents may also be upset about the diagnosis at first, many new parents also begin to feel like Down syndrome is just one part of this precious new member of their family. So, they don’t want their friends and family to be sorry about the diagnosis—any more than they would want people to be sorry their child is short or has red hair. There may also be a perceived message that others are sorry not just about the diagnosis, but that this baby (who has Down syndrome) was born at all, which is of course hurtful. Many new parents also just feel uncomfortable about being pitied during a time when they want to

celebrate their new baby. When parents hear “I’m sorry” a few times, sometimes it feels appropriate or soothing, but when they hear it again and again, it starts to grate on their nerves.

New parents adjust to the diagnosis differently, and some may want congratulations while others want empathy. Your tone can help guide the reactions of others. New parents who keep the conversation upbeat often find that their friends and family will respond positively. New parents who share that they are sad may receive comfort from loved ones, including some who say, “I’m sorry.” Finally, some parents are both sad and excited, and are not sure what they wish to hear from their loved ones. Conversations can be difficult for overwhelmed parents adjusting to the diagnosis themselves, so you may want to send an email or wait a few days to gather your thoughts more clearly.

Crafted Announcement: *We’re very excited to share that our new baby, Kate, was born on March 28 at 3:15pm. She is thriving and has the cutest jet black hair like her daddy, but she has a few health issues that will require her to stay a few extra days in the hospital. She also has Down syndrome, and even though it was a surprise for us, we are very happy to have this newest addition to our family just as she is.*

Unfiltered Announcement: *I love this little baby with all my heart, but I’m terrified because I don’t know anything about Down syndrome or what my little girl can do. I want you all to love and welcome her, but I’m scared of so many things that I don’t understand yet. I’m going to put on my brave face around all of you, and the best thing you can do for me is just to listen, love my little girl, and give me some support and also space to figure this all out. If you see me sad, just know that I’m adjusting and learning. The best thing for you to do is listen to me, but please don’t say you’re sorry.*

However, even if you set a positive tone in your announcement, you may still have someone who says they are sorry, whether it’s grandma or a neighbor who has outdated views about Down syndrome, or simply a sincere attempt from someone to empathize with your receipt of unexpected news and the natural emotional response.

Crafted Response: *Oh, please don’t be sorry. Even though I know you’re concerned about our baby and us, we’re actually very happy to have her as part of our lives, Down syndrome and all. We know she might have some extra health issues, and it will take her longer to learn, but most people with Down syndrome are doing very well these days because of better healthcare, education, and opportunities. So, we’re looking forward to a bright future with her and appreciate your support.*

Unfiltered Response: *When you say you're sorry, it makes me feel like you're sorry about my baby being born at all, even existing. Even though Down syndrome does bring some extra challenges, I am so in love with this baby, and I don't want the people around me making me feel like she was a mistake. Now, I also feel like I can't be honest with you when I'm having a bad day because you'll think I'm sorry too, so the best thing for you to do is just listen and love us.*

SPOUSAL/PARTNER COMMENTS

Spouses or partners may experience the transition from unexpected news to excitement about the baby as a couple, in this together and moving forward. However, receiving the news can be stressful, and sometimes partners are not on the same page, or not moving at the same pace. A lack of spousal or partner support can be particularly painful and difficult. Your partner may make comments that seem overly negative to you, either about Down syndrome, about the ability to parent this child, what “should” have been done prenatally, or even, in extreme cases, about separating. On one hand, they are entitled to their own emotions, fears, and concerns. Any response has to reflect a respect for their emotions. They may need more time to adjust, and will usually come around and fall in love with the baby too. On the other hand, a partner should not actively create a situation that is worse for you.

Crafted Response: *It's normal for parents to need time to adjust to a diagnosis, so let's try very hard to be patient with each other during the different stages we might go through. We do know that neither of us did anything to cause our baby to have Down syndrome. The diagnosis is just part of who he is. In time, most parents adjust very well and love their children deeply, but it's normal to go through an emotional time. It seems like you are having a very difficult time. There are so many sources of information and support that may make you feel a bit better about the future. Will you explore them with me?*

Unfiltered Response: *You are supposed to be helping me through this! I feel so alone, and the one person who is supposed to be in my corner is hurting me. Please stop. I need you. How can I do this on my own? Please, please stop saying such negative things. Please accept our baby, your baby.*

You may wish to explore some resources that can help your partner. Providing them with parent contacts, books about Down syndrome, or links to other resources may help them regain their sense of balance more quickly.

RUDE COMMENTS

Judgmental Comments

Even though most friends and family are kind when they find out about your baby's diagnosis, every so often new parents may endure rude comments from people. The comments range from people blaming new parents for their child's condition to a random stranger saying they would have terminated a pregnancy if they knew the baby would have Down syndrome. Some particularly hurtful comments may include, "I could never raise a baby with Down syndrome, I'd have terminated," or "better you than me." Other new parents have been asked, "Were you taking anything when you got pregnant?" Or they were told, "It's your fault because you are too old to have babies." Some parents have also been insensitively asked, "You're not going to have any other children, right?"

Hopefully, you won't hear any such comments, but if you do, you may feel responding to the comments will lead to social conflict. As such, you may feel you are the "bad guy" if you address the comments and may keep your reactions to yourself. Then, you may replay the comments later and have some "what I wish I said" moments. We've all been there, and there is no predicting the particular comment you may receive, but practice anyway—thinking ahead may allow you to adapt quickly.

Crafted Response: *Some response examples include the pointed, "Did you mean to say that out loud?" Other responses include: "I know everyone has opinions about what they would do, but it's not something you should share." You can also simply respond, "That was a horrible thing to say." Then you can follow up by saying, "I know you don't mean to hurt my feelings, but it really does hurt to hear you make that comment. I already feel enormously protective of my baby. I don't want to make anyone feel awkward, but it puts me in a difficult situation."*

Unfiltered Response: *What is wrong with you? Is my baby's diagnosis an open invitation for you to say whatever pops into your head? Haven't you ever heard of thinking before you speak?*

Testing Comments

Many parents can also be sensitive to discussions about whether they underwent prenatal testing, because they sense other people are judging or shaming them for not finding out about their baby's diagnosis during pregnancy. This can be especially grating after the 50th time. A family can choose whether they want optional genetic testing or not. Some find it helpful to know beforehand, and others prefer not to know. However, because testing is regularly offered to pregnant women, some people mistakenly believe it is a routine part of pregnancy.

Questions about testing come with baggage because it's very hard to tell the motives behind them. It may be simple curiosity. It may be someone contemplating pregnancy who is looking for information to use for herself, to expand her knowledge of what to expect. It may be someone looking for a source of "blame." It may be someone wishing to "subtly" insinuate that this was a problem you could have—and should have—avoided. None of these reasons justify an intrusion into your personal beliefs, choices, or thought processes. But the speakers often simply do not pick up on that intrusiveness, and perhaps they have no idea of the negative connotation the questions carry.

Crafted Response: *Some options are: "Would you mind explaining why you want to know?" or "We chose not to get testing because we felt it would cause us additional stress during the pregnancy, and even though it required some adjustment in the beginning, we are so happy to have our son." Another possibility is: "We did have some indication that there was a possibility of Down syndrome, but we made a decision as a couple to wait until we met our baby to find out if he has a diagnosis."*

Note that if you say, "I didn't get tested because I knew I would love my baby no matter what," you may unintentionally hurt other parents of children with Down syndrome who did get tested for their own reasons and also love their children.

Unfiltered Response: *I realize you're either curious or judgmental, but that question gets so old. It's a catch 22. I feel like any answer I give allows you to put me in a box that separates me from you. If I say I chose NOT to get testing, you might say I'm willfully ignorant. If I say I did get testing and continued the pregnancy, you might label me "extremist" in your mind. Either way, it makes me suspect that you think my baby could have been avoided if I had gotten tested. The truth is, I was just excited about this pregnancy and didn't want to make it complicated, and now I have a baby I love who also has Down syndrome. I just want you to appreciate him with-*

out asking questions that are really too personal. Would you want me to ask your mom if she got tested for the “rude gene” when she was pregnant with you?

Down Syndrome Stereotype Comments

Most parents have experienced a feeling of worry or panic about the future of their child with Down syndrome. Though potential medical issues may be a point of immediate concern, worries often leap to school, adolescence, or adulthood upon receiving the diagnosis. Often, only after dealing with the current issues at hand can we take the time to process the news and learn about the possibilities for people with Down syndrome. Our friends and relatives may also be on a similar journey, but some may express their fears in a certain way or at a time when we are vulnerable, and not empowered yet by accurate information. Such fears may be expressed as, “He’ll live with you forever” or “People will make fun of him.” We cannot be sure why people make these comments to new parents. Perhaps they simply have no filter? Maybe they believe you are sharing these concerns together with them in some type of group processing of information. Maybe they feel they must “tell it like it is” (or at least as they see it) as a version of tough love. Who knows?

Crafted Response: *Actually, I think we all have a lot to learn about Down syndrome, but even in such a short time, we have learned so much about the possibilities for people with Down syndrome. We are trying to separate the baseless fears from areas of concern and learn about ways to help our baby. I will send you a great resource that will help you learn too.*

Unfiltered Response: *Okay Captain Obvious, you are not as informed as you think you are. Yes, with your amazing people skills you’ve managed to trip over some natural concerns of a new parent and have phrased them in your typical doomsday voice. But your confident predictions show a real lack of understanding of the diversity, progress, and potential of people with Down syndrome. How exactly are your comments helpful?*

OPTIMISTIC COMMENTS

Parental “Fluff” Comments

These comments are usually shared by well-meaning people who are trying to boost your spirits, but they can sometimes be problematic. You are at your most

vulnerable, maybe feeling lost and afraid, and emotionally volatile. In an attempt to comfort you, people may tell you, “Special babies are sent to special people,” or that you are amazingly strong, or you were chosen. One parent said she was told, “You shouldn’t be worried or sad. You should feel blessed that you were chosen to be this little girl’s parents.” The person speaking may truly feel such comments are comforting, and, to some parents, they are. But other parents react strongly to comments that qualify who they are based on a diagnosis.

Most parents do arrive at a place where they feel lucky to be the parent of a child with Down syndrome. However, you may find these comments difficult when the diagnosis is still fresh and raw, and you might need time to work through your own feelings about it. You may also be worried about the unknown and it feels like overly optimistic comments are dismissing your feelings as if you are silly. Sometimes you need time to adjust before you’re ready for the cheerleaders, even though you may really want that later. You may also feel uncomfortable about comments that define who you are as a parent based on your baby’s diagnosis.

Sometimes this parental “specialness” can take on a “you not me” tone, such as, “God would never give me a baby with Down syndrome because he knows I couldn’t handle it.” Sometimes, people use the common platitude, “God does not give you more than you can handle.” This last one is tricky: some people are comforted by it, while others feel their current emotional state is being dismissed, or that the speaker is again reinforcing the idea that there must be something special about you the parent.

Crafted Response: *I know you are trying to make me feel better right now, and I do appreciate it. I’m really thankful that other parents have told me they have experienced the same emotional turmoil, and that it is perfectly normal. I know I’ll move on from these feelings, but I’m just not there yet. Every time someone tells me how special I am, it makes me feel inadequate and not up to the task.*

Unfiltered Response: *I’m not any more special, strong, or blessed than I was a few months ago, except right now I feel lost, afraid, and wonder, “Why me?” or “Why my baby?” I’m worried about the future. I can’t just turn those feelings off. Please don’t put me on a pedestal. I feel really vulnerable right now, and a pedestal is the last place I want to be! Rather than making me feel better, it makes me feel worse. It makes me think you are making everything right in your world by classifying me as the one who is “supposed” to have a child with special needs. Well I don’t feel like I fit*

the role you are writing for me. Let me feel what I want to feel—don't tell me how I'm supposed to feel or how I'm supposed to see myself.

Down Syndrome “Fluff” Comments

Many people will try to comfort you with positive comments about Down syndrome, and many new parents will appreciate these words. However, sometimes the comments don't sound quite right, especially when said by someone who has not been where you are. These comments may include remarks that it's “no big deal” or “a blessing” or that “people with Down syndrome are always happy, loving, and innocent.” You may experience many of these things with your child and see your child as happy, loving, and a blessing to you and your entire family.

However, these comments can feel like your child is being stripped of his or her individuality, or that they are losing their complexity as an individual. You may feel like your child is being described as two dimensional rather than a complex person capable of a vast array of emotions like everyone else. This certainly is not what the speaker intends, but often it can be what we hear. It can also make you feel like they are telling you your emotions are unwarranted or silly.

Crafted Response: *Well, in talking to parents of children with Down syndrome, I've learned that their kids are wonderful, and, just like other kids, they have the full range of emotions, from happiness, to anger, to love, to sadness. Like any other baby, we'll get to know her personality as she grows. I'm glad you are so willing to accept our baby for who she is. We are still grappling with what issues she may face later, so we are still a little apprehensive. Thanks so much for supporting us.*

Unfiltered Response: *I know you mean well, but my baby is not a puppy. She's a human being, a unique individual. I may still be learning about Down syndrome, but I know enough to know people are not all the same. And it's easy for you to say “no big deal” — you aren't dealing with reconstructing the vision of the future for your child before even meeting her.*

Backhanded Compliment Comments

Certain remarks made to boost your spirits and give you hope often backfire. They do not sound quite right to you, but it can be difficult to pinpoint the reason. Your helpful aunt reassures you, “They can go to special schools, you know.” Other loved ones try to boost your spirits by letting you know that “those

people” can even do many things—ride a bike, spell their name, go to school, or work at the grocery store. What is it about these statements that sometimes rub new parents the wrong way? Perhaps it is the overuse of the collective word “they” or “those people,” or “these kids” in the list of accomplishments—in a way that is both over generalizing and stereotyping. Are “they” a herd of sheep? Do “they” move lock-step? Maybe it is the seemingly low level of expectations that follow the words, “they can even.” Though in the parents will celebrate milestones both big and small in the future, these statements seem to identify an end goal that can seem both limiting and often cliché.

Sometimes, rather than the vague collective identifier, your loved one will mention the neighbor’s uncle’s friend’s son as an example of what your life or your child’s life will be like. While connecting you to others in the Down syndrome community can be a wonderful gesture, holding up another person as if they were a mirror can evoke feelings of anger, resentment, and protectiveness.

Crafted Response: *Actually, I am learning so much about people with Down syndrome, especially how different each person can be from another. I am sure we’ll be continually learning about what our child can and will do as she grows, what her specific challenges and strengths will be. We are excited to see what her career goals will be one day.*

Unfiltered Response: *“They, they, they.” Really? How about “Ellie”? As in “Ellie is so cute.” I really do not need to hear a rehash of the incidental glimpses of Down syndrome you have seen in your life when you were not really paying attention.*

PSYCHIC COMMENTS

Loved ones might also have a knack for saying things that leave us shaking our heads. One such statement is, “This is what I was afraid was going to happen!” Another mystical statement is, “You know I had a dream that this happened to you.” One comment heard by a new parent is, “The minute I found out you were pregnant—I knew your baby was going to have Down syndrome.” We are not exactly certain why people need to make sure their predictions have been duly noted. Is it that they wish their psychic powers to be officially acknowledged?

Crafted Response: *Absolute silence, or perhaps a noncommittal but polite, “Interesting.”*

Unfiltered Response: *Seriously? You are looking for “credit” right now? My baby is all about you and your sixth sense?*

IGNORANT/ CURIOUS COMMENTS

By ignorant, we mean “unknowledgeable”—not the slang equivalent of “rude.” And yes, we give a lot of slack to the public at large. Of course they don’t know a lot about Down syndrome—why would they unless they love someone with Down syndrome? But, with a new baby and a fresh diagnosis, you will likely be sensitive, and the things you may have once said to another person may now bother you. And the questions—they ask so many questions that you cannot answer. Sometimes that can accentuate your own lack of knowledge. Here are samples of some comments moms have heard:

“She doesn’t look like she has Down syndrome. Your baby is cuter than those other babies.”

Crafted Response: *Well, people with Down syndrome may have some similar features, and sometimes that shows up a little later. But, the appearances of people with Down syndrome are also very diverse—like the rest of the people in the world. I think she looks a lot like Daddy (or Mommy or sister). I’ve been looking at pictures of kids with Down syndrome. I’ve seen so many cute children, and I know as she grows she’ll have her own unique look.*

Unfiltered Response: *How am I supposed to take that comment? This baby has Down syndrome. Your comment implies that looking like you have Down syndrome is a bad thing—how is that appropriate to say to the parent of a child with a diagnosis?*

“Maybe she’ll be high functioning” or “Maybe she’ll just have a little Down syndrome.”

Crafted Response: *Well, she has Trisomy 21, which means she has an extra chromosome in every cell in her body. You either have it or you don’t. We’ll just have to wait and see about the medical issues. As far as cognitive ability, there is a wide variation, and we really won’t know until she’s older what that outcome will be—much like with any child. But the most important thing is that she is our daughter. She is cute, and we love her.*

Unfiltered Response: *I can’t believe people expect me to know the answer to this question. She’s a week old! Can anyone tell how their child will turn out or how smart they will be right after they’re born? I know this is a version of being supportive, but it makes me feel “put on the spot” while I’m still learning about the possibilities for this baby. How can I be a teacher when I feel like I’m a student on the first day of school?*

INCREASING SENSITIVITY TO INAPPROPRIATE VOCABULARY

It could be a line in a TV series, dialogue in a movie, slurs in a book, or the slang we hear bantered about by our family and friends. Usually people using such terms do not intend to insult people with intellectual disabilities, but certain slang words tossed around casually can be hurtful to the families of people with Down syndrome.

Sometimes it's actual references to intellectual disability—most often the word “retarded” thrown about by middle schoolers and adults alike, but other times it may be references to “the short bus” or other generalized comments. These may have been words that previously flew under your radar or that you used in the past. Now, if the conversation around you were in written dialogue form, the words might be highlighted, bolded, and underlined. Their impact can range from discomfort to pain, and often you just do not know what to say. You may feel that saying something will make the other person uncomfortable—you may feel like you are creating a social conflict. But if you say nothing, you may feel like you are not standing up for your child.

First, these reactions are completely normal, and you don't have to be an outspoken advocate, especially now when you may be feeling vulnerable. It's okay to just walk away, and wait until you feel more confident. And if these words don't bother you, that's okay too. As you prepare for interaction with the Down syndrome community, you should examine your vocabulary to make sure you are not hurting the feelings of other parents, but there is no rule book that says you should be sensitive to slang.

Second, if the slang now hurts greatly, and you want to say something, your best approach is to be proactive rather than reactive. Sending your thoughts out to loved ones in an organized, thoughtful, and non-judgmental way that anticipates their responses may go much further than an emotional on-the-spot reaction. If you have previously used these words in slang, explain that and ask your loved ones to come along on your journey towards kinder vocabulary.

Family Stories

I think the thing that annoyed me was the overarching comment that children with Down syndrome are the happiest babies, etc. I generally just replied (since I have had the benefit of working with numerous children with Down syndrome) that yes

they can be so sweet, but they can be mischievous, frustrated, etc. just like any other kid! —Sabrina

Scarlett's diagnosis was a surprise at birth. We got plenty of annoying comments. Most of them were with good intentions and out of ignorance. We tried to focus on intentions instead of words. We also kindly and calmly corrected others. We explained how the comment could be seen as hurtful. We tried to educate others when we could. —Laura

It was those annoying platitudes that I didn't want to hear. What I really needed was for people to just HEAR me: all the fears, concerns, hopes, questions, anger. All of it, without judging me or trying to make me feel better. As well-meaning as they are, I believe that people with platitudes are actually trying to make you feel better so that they can feel better because they just can't handle your tears. I just wanted someone to be there without trying to fix it. —Heather

I remember telling my sister, and it did not even faze her. She right away congratulated us and shared such positivity and asked the questions about labor, her height and weight, etc. She said times have changed and there is so much more opportunities for those with Down syndrome. —Danielle

[*Related Articles on DownSyndromePregnancy.org*](#)

You can visit [DownSyndromePregnancy.org](#) for articles such as, [*"Dealing with People and Comments."*](#)

This article also includes templates for emails you can copy and paste to gently ask friends and family to use kinder words and avoid offensive slang.



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PREPARING YOUR OTHER CHILDREN

After adjusting to the news of a Down syndrome diagnosis, you may be concerned about the future for your other children and wonder how a new baby with a disability might impact them. You may worry about whether the other siblings will be teased, feel resentment, receive enough attention, feel embarrassed, or be impatient when dealing with their brother or sister. These are all real concerns for any set of siblings. However, research shows that most siblings of people with Down syndrome say the positives outweigh the negatives, and there are benefits to having a brother or sister with Down syndrome.⁹

Research shows that the siblings of children with Down syndrome tend to be more compassionate and well-adjusted,¹⁰ and they have friendships and aca-

9 Skotko, B. & Levine, S. (2006). What the other children are thinking: Brothers and sisters of persons with Down syndrome. *American Journal of Medical Genetics Part C*, 142C:180-186.

10 Dykens, E. M. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *Mental Retardation*, 43:360-364.

demic performance similar to their peers who don't have a sibling with Down syndrome.¹¹

Dr. Brian Skotko, a notable researcher who has a sister with Down syndrome, conducted a survey of hundreds of siblings across the country to find out what they thought of their brother or sister with Down syndrome, and he learned the following:

- More than 96% said they loved their sibling with Down syndrome.
- 94% of older siblings said they were proud of their loved one with Down syndrome.
- 88% of those older brothers and sisters also said they were better people because of their brother or sister.
- More than 90% planned to remain involved in their sibling's life as they grew older.
- Less than 10% felt embarrassed by their brother or sister with Down syndrome.
- Less than 5% said they'd like to trade their sibling.

Dr. Skotko often jokes that it would be interesting to compare how many siblings would like to trade their brother or sister who doesn't have Down syndrome. Overall, the study shows that the vast majority of siblings have positive and rewarding relationships with their brother or sister with Down syndrome.¹²

While a child may experience various challenges associated with their condition, their siblings by and large view them as individuals and develop typical sibling relationships including rivalries, fierce protectiveness, playfulness, occasional sibling squabbles, and genuine love and respect.

However, this emotional development and maturity is certainly fostered by parents who encourage open conversations, as well as mutual respect and appreciation.

11 Cuskelly M. & Gunn P. (2007). Adjustment of children who have a sibling with Down syndrome: Perspectives of mothers, fathers and children. *Journal of Intellectual Disability Research*, 50(12):917-925.

12 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Having a brother or sister with Down syndrome: Perspectives from siblings. *American Journal of Medical Genetics Part A*, 155:2348-2359.

TELLING YOUR OTHER CHILDREN

What and when you tell your other children depends on a number of factors, including their age, maturity, disposition, your state of mind, and anticipated medical issues. Children younger than five often don't grasp what Down syndrome means and might not notice any difference for a while.

For very young children, some parents choose not to explain until their child is old enough to understand. They might reveal the information in steps by explaining that the baby is going to need extra help learning to walk or talk, or they might simply address the most pressing issue by explaining that the baby will need surgery to repair his heart. And yet other parents choose to identify the condition right away and then gradually explain what it means.

Dr. Skotko says that “many parents find it helpful to read the children’s books from Woodbine House which contain characters who have Down syndrome. At first, reading the story without drawing attention to the fact that the child has Down syndrome is helpful at reading time. Then, as the book becomes a favorite, the parents can point out that one character has Down syndrome, which can be a nice way to introduce the topic to young siblings.”

Elementary school-aged children typically can understand at an age-appropriate level. You might explain to a first-grader that she has a new brother, which is exciting. Then you might explain how every person is born with different characteristics, such as eye color, hair color, and height. Then you can explain that one characteristic of this new brother is that he has Down syndrome. This usually means his muscles are weaker, he might have trouble speaking, and it might take longer for him to learn. A fifth-grader, on the other hand, can usually understand an explanation about genetics when a person has an extra chromosome that causes developmental disabilities and low muscle tone. Regardless of your explanation, you can ask your child about concerns and address them directly.

Some questions to ask yourself before sharing the news with your child:

- Will my child understand if I share the diagnosis? If not, should I share the diagnosis in steps?
- How should I present the information in order to be age-appropriate? How much information should I share?
- What is my emotional state? Should I explain some of my fears and concerns to explain if I have been acting differently, or should I wait until my emotions have settled?

Consider these factors when you decide to share the news with your child and then pick a time when you can sit down without distractions and address any concerns.

ADDRESSING CONCERNS

Below are sample responses to common concerns expressed by siblings.

“Why are you so sad?”

Sometimes I might seem sad. This is because I love your brother and worry about him just like I love and worry about you. Your brother will be okay, and I will be okay, but it just takes a little while for me to learn and understand what I need to do to help him.

“Can I still play with my brother?”

Absolutely! It might take a little longer for your brother to learn to talk or walk, but he will do those things. And you can help him. He may have a therapist who comes to the house and teaches us how to play with him, and you can help by playing some of the games the therapist teaches us.

“Will he be okay?”

Your brother has a heart condition that will need surgery, but once the doctors fix that, he will be a healthy boy and we expect that he will be healthy and do just fine.

“Will you still be around to help me?”

Of course! Your brother will probably need some extra time in the beginning. This is true for all new babies. He also might have to stay at the hospital a little longer, and he might need surgery when he is a few months old. This will mean that I will have to spend more time at the hospital. Of course, a newborn always needs more attention because I have to feed him and change his diapers, just like I did for you. But, it won't take too long for things to settle down and then I will spend time with all of you. While I'm away at the hospital, your grandma will be here to help until I come back, and she will bring you to the hospital to see us.

KEEPING IT REAL

It's important to remind your children that a Down syndrome diagnosis is just one characteristic of their brother or sister. They will have lots of questions, and it's important to address them as best you can. However, your children will soon get over the diagnosis and simply see your child with Down syndrome as "Andy" or "Gabby"—just another ordinary member of your family.

You can help your children develop an attachment to their sibling by encouraging them to read or sing or make funny faces at their new brother or sister. They can help change diapers, feed the baby bottles, or put lotion on their brother or sister at bedtime. First and foremost, this new little baby is a member of your family and their brother or sister.

"Your child with Down syndrome, ideally after health issues are resolved, will be a piece of the pie that is your family," explains Jennifer Bekins, a speech therapist who also has three siblings with Down syndrome. "They shouldn't be the hub of the wheel."

SIBLING RESOURCES

You can help your children understand their new brother or sister's condition with the following resources:

Books:

- *Common Threads: Celebrating Life with Down syndrome* by Cynthia Kidder and Brian Skotko

For younger children:

- *47 Strings: Tessa's Special Code* by Becky Carey
- *We'll Paint the Octopus Red* by Stephanie Stuve-Bodeen
- *I Can, Can You?* by Marjorie W. Pitzer
- *My Friend Isabelle* by Eliza Woloson
- *Eli, Included* by Michelle Sullivan

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- *What's Inside Me is Inside You, Too: My Chromosomes Make me Unique* by Deslie Webb Quinby
 - *This is Ella* by Krista Ewart
 - *Hannah's Down syndrome Super Powers* by Lori Leigh Yarborough
 - *My Sister, Alicia May* by Nancy Tupper Ling

For older children, teens, and adult siblings:

- *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters* by Brian Skotko & Susan P. Levine
- *The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs* by Don Meyer
- *Thicker Than Water: Essays by Adult Siblings of People with Disabilities* by Don Meyer
- *Gifts 2: How People with Down Syndrome Enrich the World* by Kathryn Lynard Soper
- *National Down Syndrome Congress (NDSC) Adult Sibling Toolkit*

Films:

- *Deedah*
A short film narrated by 7-year-old Charlotte May about her brother Jonathon, who has Down syndrome and calls her "Deedah." Charlotte forthrightly answers questions about Jonathon, including love, bullying, uniqueness, delays, and humor. It may be a useful way to illustrate the future for your other children.
- *Brian Skotko and Sue Levine's Down Syndrome Sibling Book: YouTube Channel*
Covers a range of different topics, such as speaking up for your sibling, finding private time, coping if a sibling is embarrassing, and more.
- *Just Like You: Down Syndrome*
This film on YouTube explains Down syndrome and answers many frequently asked questions from the perspective of teens with the condition and their friends. This film is particularly helpful for adolescents and young adults who want to know how to build relationships with a peer who has Down syndrome.
- *Special Books by Special Kids YouTube channel* by Chris Ulmer
This YouTube channel highlights interviews with kids who have different kinds of disabilities, including sibling pairs.

Conferences and workshops:

Each year the national *NDSC Conference* offers a Brothers and Sisters Conference for siblings who are school-age, currently fourth grade and up. This conference usually includes workshops about different Down syndrome issues, sharing sessions with other siblings, guest speakers, and activities.

Other siblings

While you can reach out to other siblings at the national conference and at local events, you can also meet other siblings through your local support organization or in your community. Sometimes it can help your children to meet other siblings so they can see other families like theirs and realize they are not alone.

HAVING MORE CHILDREN

Some parents are concerned about having other children and their chances of having another child with Down syndrome. Please remember, no decisions need to be made with a newborn in your lap. Parents usually need time to adjust emotionally, and feelings may change over time.

After you gather your bearings, you can find out your odds for having another baby with Down syndrome and how you can prepare for the future by consulting with a genetic counselor or geneticist.

You can also speak with other parents from your local organization who have had subsequent children to find out how they made their decision. Many new parents have heightened concerns about their chances of having another baby with Down syndrome, but those fears often fade over time as they get to know their child. In addition, those parents who have multiple children usually find that the siblings have the same meaningful and close relationships—no matter whether the child with Down syndrome is older or younger than the other children.

This is not a decision you have to make right now. You can revisit this when your child is a little older. In fact, as time passes, some parents choose to adopt another child with Down syndrome once they have adjusted to life with their child.

Family Stories about Siblings

Scarlett's siblings were 5, 4, and 2 when she was born. We waited a month or two to tell them while I learned what to say. Finally, we sat them down before bedtime. We explained that Scarlett's body was made different. We told them she can do anything but she might have to work harder or longer. At the end of the conversation my 5 year old said, "Alright, so she has an extra crumb?" I said yes with out correcting the "crumb." Then he asked why we waited so long to tell him. To him it was not a big deal. She is his sister, and he loves her unconditionally. —Laura

We read several books for siblings about Down syndrome. We told them their brother needs extra help learning to walk and talk, and now they are great therapy helpers. They love him as their brother. —Katherine

My older brother, Andy, has Down syndrome. We're only two years apart, so we've always been super close. In most ways, Andy is a lot like any older brother. He's moody sometimes, and he pushes my buttons, but I know he really cares about me.

However, there are a few things that are a bit different. Growing up, we always had speech therapists around, so I learned to speak really quickly, and eloquently! I also learned sign language because that was Andy's main way of communication before he started speaking more. When we went to school, Andy was always suuuper popular, so I was "Andy's little sister" to older kids (which was nice because they probably wouldn't have talked to me otherwise!).

There were hard things of course, like when I felt he was left out or left behind or when people would make insensitive comments about disabilities around me. The hard things were tough, but I wouldn't change Andy for anything. He's one of the most independent, positive, and talented people I know. I'm so proud of him!

For me? Being his sister has made me more sensitive and understanding (I hope). I also teach my friends to be sensitive about their language. I have become an advocate for people with disabilities.

I love my brother. He's made me a better person, and I would never change him for anything. —Kate

Related Articles

You can visit DownSyndromePregnancy.org for articles such as, "[Twins](#)," "[Siblings Speak Out: Jenni Newbury](#)," "[Sibling Perspectives on Down Syndrome](#)," and "[Siblings Speak Out: Jennifer Meyers Bekins, MS, CCC-SLP](#)"



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BREASTFEEDING

This chapter gives a basic overview for breastfeeding your baby with Down syndrome, but there is a wealth of information available to you on this topic. For a complete discussion of breastfeeding strategies for babies with Down syndrome—including breastfeeding through health challenges, positioning a baby with low muscle tone, raising the calorie content of milk, stories from moms at every stage, and more—please see *“Breastfeeding Your Baby with Down Syndrome”* edited by Ella Cullen from Julia’s Way on the Down Syndrome Pregnancy website. Julia’s Way also shares a video, pamphlet, and other resources for nursing mothers.

Many new moms hope to breastfeed their babies for nutritional and bonding reasons. For the child with Down syndrome, breastfeeding has additional benefits for oral motor development, as breastfeeding exercises more muscles in the mouth. Breastfeeding also has immunity advantages that benefit babies with Down syndrome, especially if they have cardiac or other health issues.

Many babies breastfeed with no problems. However, others have difficulty because of a weak suck, sleepiness, tongue thrust, or other medical issues such as heart defects. Moms can try many different techniques to have a successful breastfeeding relationship even with these challenges. We highly recommend meeting with someone who is experienced with Down syndrome-related

breastfeeding issues, perhaps an occupational therapist or a lactation consultant at a children's hospital. Meeting with a professional to discuss potential issues and solutions and to develop a proactive plan may greatly increase your chances of a successful breastfeeding relationship.

Many of the general tips and techniques for breastfeeding also apply to breastfeeding your baby with Down syndrome. There is an extensive amount of literature that covers the basics—for example, positioning, skin-to-skin contact, timings of feedings, and use of a nipple shield. You might want to read the literature and attend a breastfeeding course to be successful, particularly if you are a first-time mother.

You might also want to get a hospital grade pump if initial health problems or latching problems exist. If you need to pump long-term, most hospitals also rent high-quality breast pumps for a reasonable price. The cost may also be covered by your insurance, or you may be able to deduct the cost as a medical expense.

If your baby has health problems or latching problems, pumping right away will allow you to maintain your milk supply. Multiple approaches can help you continue to work on breastfeeding during this time, and you may find your baby will take to the breast weeks or even months later. A breast pump may allow you to provide your baby the benefits of breast milk while keeping up your supply so you can teach your baby to breastfeed as soon as possible.

It is also important to monitor the growth and weight gain of any breastfed infant during the first weeks to make sure the baby is getting enough calories. A lactation consultant or pediatrician may give you additional instructions about how to increase your baby's caloric intake based on the specific nutrition needs of your baby.

A lactation consultant may advise you to pump a little bit right before feeding to get the milk flowing, which can make it easier for the baby to nurse. She may also recommend that you pump after a feeding to express some of the fat-rich "hind milk" which you can bottle-feed to the baby, making sure baby gets enough calories.

Your pediatrician may recommend that you supplement with formula. This can meet some concerns about calories or low milk supply. Your doctor may recommend that you mix high-calorie infant formula with expressed breast milk at a specific ratio, giving your baby the benefits of breast milk but rich calories that may help a baby with feeding or cardiac issues.

If you have difficulties, you can contact a lactation consultant, a La Leche League consultant, Julia's Way, or a cardiac lactation consultant if one is available to you. Request someone experienced in this area. Also, you can search online or post a question about breastfeeding in many mother-support forums. Many moms are happy to share their experiences.

Family Stories

From Nancy Iannone, sharing her successful breastfeeding experience as a mom of four whose youngest had Down syndrome, hypothyroidism, and a heart condition:

Gabby was my fourth child, and I had breastfed my other children each for at least a year. I wanted to breastfeed, but I did not want to risk my baby's health with insufficient calories. My cardiologist urged long-term breast milk, and she sent me to cardiac lactation consultants at the local children's hospital. These women talked about potential challenges and solutions.

Gabby was born with a tongue thrust (pushing the tongue out strongly), hypothyroidism, and a heart defect, making her unable to breastfeed at first. My lactation consultants had prepared me for this possibility, and we talked about the use of a pump. I pumped starting two hours after delivery, and after some attempts, resigned myself to long-term pumping. We added powdered formula directly to the breast milk at a specific ratio so that Gabby received extra calories.

At eight weeks of age, Gabby suddenly became extremely hungry and started nursing out of the blue. Eventually she refused bottles and continued to nurse until she was over two years old.

From Sarah Hartway, describing her son who breastfed for almost a year with only a few complications:

My son was diagnosed with Down syndrome an hour after birth. I had breastfed my daughter successfully, so that gave me some confidence, and we were successful. Adam needed extra help learning to latch on for the first few days but then did great. The only issues we had were that he seemed to have diminished appetite followed by slowed growth at about three months, but we worked through that with some help. He's 14 now, and nobody would ever guess he had growth concerns as an infant! He nursed consistently until 11 months when he quit cold turkey. That hadn't been my plan, but it sure was his.

From Megan Landmeier, talking about her breastfeeding challenges she resolved with help:

For the first two weeks Ellie was on IV nutrition due to gastrointestinal atresia. I pumped and bottlefed after that. We tried breastfeeding with the nipple shield, and the lactation consultant thought she'd get it in time. For the first three months I mostly pumped. I went back to work when Ellie was eight-weeks-old, and my supply dropped. At four months, I was able to stop pumping because Ellie was able to take half her feeds at the breast and half formula. My body couldn't keep up with her appetite!

BREASTFEEDING RESOURCES

- [Organization: Julia's Way](#)
- [Book: Breastfeeding & Down Syndrome: A Comprehensive Guide for Mothers and Medical Professionals](#) edited by Ella Gray Cullen
- [Nursing and Down Syndrome: A Short Guide to Breastfeeding Your Baby](#)
- [Julia's Way Movie: Nursing Down Syndrome](#)
- [Canadian Down Syndrome Society: Breastfeeding a Baby with Down Syndrome](#)
- [La Leche League](#)
- [Children's Hospitals and Clinics of Minnesota: Breastfeeding an Infant with Down Syndrome](#)

COPING WITH UNRESOLVABLE BREASTFEEDING CHALLENGES

Some babies with Down syndrome may not breastfeed, even if you have experience breastfeeding previous children. If this is the case, please try not to blame yourself or feel guilty. This may be painful for women who want to breastfeed, but the important thing is to stay mentally and physically healthy, enjoy your baby, and keep your baby loved and well fed.

Many moms commit to pumping long-term, while others go to formula feeding. Finding what works best for you and your baby is what is most important. Of course, you can also still cuddle and talk to your baby while you bottle-feed. Oral motor stimulation and infant massage can strengthen your baby's muscle tone and enhance the bonding experience. For more information about oral

motor exercises, you can consult with your baby's occupational therapist and see "Therapy/Sign Language Resources" on page 99. For more information about infant massage, this [Parents article](#) gives you the basics and resources for more details.

Family Stories

From Stephanie Meredith, describing how she struggled with breastfeeding and found perspective:

I worked very hard to nurse my first son with Down syndrome and ended up pumping for six weeks and then bottle-feeding because I had some anatomy problems and was inexperienced. Preparation and relaxation would have done wonders for me. The main point is to enjoy being a mom without putting so much pressure on yourself. Breastfeeding is a wonderful experience, but you can still have a strong bond, a healthy child, and a happy experience with your baby whatever the outcome. My son is now grown and very healthy, happy, and independent.

Related Articles on DownSyndromePregnancy.org

You can visit DownSyndromePregnancy.org for articles such as, "[Breastfeeding Your Baby with Down Syndrome.](#)"

This article lists more breastfeeding resources and includes personal breastfeeding stories from many mothers



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UNDERSTANDING FIRST YEAR MEDICAL ISSUES

Even though babies with Down syndrome have higher chances for some medical issues, remember that your baby will likely only have some of those issues or none at all. Also, the vast majority of these conditions are treatable, and most major health issues (including heart conditions and digestive issues) can be corrected with surgery during your baby's first two years. In fact, advances in health care have improved so significantly for these medical conditions that the average life expectancy for people with Down syndrome has almost doubled in the past few decades.¹³

If your baby has relatively minor issues or no complications, your baby could come home with you at the usual time after delivery. However, it is also possible that other issues may require monitoring, a stay in the Newborn Intensive Care Unit (NICU), or a surgery scheduled for months later.

13 Yang, Q., Rasmussen, S.A., Friedman, J.M. (2002). Mortality associated with Down's syndrome in the USA from 1983 to 1997: A population-based study. *Lancet*, 359:1019-25.

EXAMINING YOUR NEWBORN

If you received a diagnosis at birth, it's likely your pediatrician or neonatologist recognized some common physical characteristics of Down syndrome while examining your baby. Some of these features include almond-shaped eyes with epicanthal folds; smaller ears; a broad, flat nasal bridge; a relaxed tongue; thickness on the back of the neck; palmer creases on the hands; or a sandal-gap between the toes. Your baby will likely have several of these physical traits, but not all of them.

Your health care provider also may have noticed your baby has relaxed muscle tone and joints. Generally, babies with Down syndrome have low muscle tone, sometimes described as hypotonia. Typically, babies with Down syndrome also have loose joints. The combination of low muscle tone and loose joints is a physical sign of Down syndrome and presents a need for caution in the way in which your newborn is held. Proper head support and swaddling are important. Ask your pediatrician for more information.

Then, your pediatrician may have looked closely for issues that occur more frequently in babies with Down syndrome, such as heart issues, gastrointestinal conditions, vision impairments, and feeding issues. Your pediatrician may also order a complete blood count (CBC) and an ultrasound of the kidneys.

Medical providers also usually screen for hypothyroidism and congenital hearing issues with an automated auditory brainstem response (ABR or BAER) test. These screens are common for most newborns.

Ideally, you were able to hold and snuggle your baby immediately after delivery, but your baby may have been taken to the NICU for further evaluation, monitoring, and treatment. This is temporary and babies are sent home as soon as they are stable. For more information about coping during a NICU stay, see "Coping with Surgery or a NICU Stay" on page 78.

GETTING REFERRALS TO SPECIALISTS

Once the diagnosis has been confirmed, your medical provider may suggest you see other medical professionals for information or treatment. The following is a list of possible specialists. Whether you are referred to one or more of these specialists will depend on many factors particular to your baby and access to specialized health care.

-
1. **Geneticist or Genetic Counselor.** Genetic counselors and geneticists will explain genetic test results; give you more information about Down syndrome; provide the likelihood of recurrence in future pregnancies; and evaluate your genetic family history. Genetic counselors can also be reliable resources with referrals to local services and connections with local families and support organizations. In addition, geneticists can provide overall management and coordination of care.

You can perform your own search at the [National Society of Genetic Counselors](#) or the [American College of Medical Genetics and Genomics](#).

2. **Developmental Pediatrician.** To provide you with more information, your medical provider may refer your baby to a physician with expertise in treating children with developmental delays. You may also access a Down syndrome clinic online or in person, if one is located in your area. See “Finding a Down Syndrome Clinic” on page 118 for more information.
3. **Pediatric Cardiologist.** Your medical care provider may refer your child to an expert in cardiology for a consultation and an echocardiogram. See “Learning About Heart Defects” on page 75 for more information.
4. **Gastrointestinal (GI) Specialist.** Your medical care provider may refer your baby to a GI specialist for a consultation and possible follow-up care, if a GI issue is suspected or confirmed. See “Understanding Gastrointestinal Issues” on page 73 for more information.
5. **Ophthalmologist.** Because children with Down syndrome have increased chances for vision issues, your child may be referred to a vision specialist for evaluation.
6. **Ear, Nose, and Throat Specialist (ENT) or Otolaryngologist.** Your baby may also be referred to an ENT for a hearing evaluation because children with Down syndrome have higher chances for hearing loss.
7. **Endocrinologist.** Your medical care provider may refer your baby to an endocrinologist if blood tests indicate that his or her thyroid hormone levels are abnormal.
8. **Lactation Consultant or similar expert.** If you wish to breastfeed your newborn, a consultation with a lactation consultant, occupational therapist (OT), or speech/language pathologist (SLP) who is knowledgeable about Down

syndrome or cardiac issues may increase the chances of a successful breastfeeding experience. See “Breastfeeding” on page 59 for more information.

9. Other specialists. If your baby has other issues, you may be referred to an expert in the appropriate field, such as a pulmonologist for breathing issues.

EVALUATING YOUR MEDICAL PROVIDERS

Most children with Down syndrome receive treatment from their neighborhood pediatrician or family doctor, like any other baby. Babies with Down syndrome may also see specialists for specific health issues as mentioned above or a developmental pediatrician annually. However, a diagnosis of Down syndrome adds an additional layer to the typical well-baby care and may prompt you to ask the following questions:

1. What is your provider’s experience treating babies with Down syndrome or any other specialized conditions your baby might have, like a heart or GI condition?

When evaluating your medical providers, you may consider whether they have training, skills, and experience to meet the needs of a child with Down syndrome. Parents from your local support group may know the names of particularly helpful and experienced pediatricians, family doctors, and specialists in your area. However, some medical providers who don’t have much experience can still be wonderful if they are particularly attentive, kind, and determined to learn the latest recommendations for children with Down syndrome.

2. Does your medical provider stay up-to-date on recommendations for children with Down syndrome?

The American Academy of Pediatrics offers guidelines for children with Down syndrome, and research, treatments, and technology always progress. Your child with Down syndrome will benefit most from seeing medical providers who stay current on the latest recommendations, literature, and research.

3. How is your provider’s responsiveness in coordinating care, sending timely referrals, and communicating with other specialists?

Your baby may receive care from more than one medical professional. These professionals will work together to monitor your baby’s health, so it is impor-

tant that they communicate clearly and effectively.

4. How did your health care provider react to the diagnosis? Does your medical provider treat your child like an individual?

Most parents report that their health care providers are supportive and treat their patients with Down syndrome like any other beautiful baby in the office. These providers focus on monitoring and managing the health of the baby while also watching more closely for some health conditions more common in people with Down syndrome. A small minority of parents report difficulties with their providers, including insensitive comments or negative attitudes about their child.

If you are uncomfortable with anything your health care provider has said, you can discuss these issues directly, explaining how words impact you. The provider may not realize how their words, tone, or attitude impact you and your family. Beyond the level of sensitivity and misunderstanding, some health care providers may behave inappropriately when treating a patient with Down syndrome. These issues may not be resolvable by discussion, or you may feel too hurt or uncomfortable to discuss it. If you find that your health care provider is inappropriately negative toward you or your baby, consider finding a new health care provider. Your local support organization may recommend a more supportive provider.

UNDERSTANDING NEWBORN MEDICAL CARE AND ISSUES

Newborns with Down syndrome may experience a range of common minor or more complicated issues. You may find your baby does not have any of these things, but they are more frequent for this population as a whole. You should expect your pediatrician to follow certain protocols for tests and referrals to specialists even if no issue is detected. You do not need to be concerned just because a provider orders tests. Often, they are following protocol based on the American Academy of Pediatrics Down syndrome guidelines to rule out medical conditions that occur more commonly in the Down syndrome population—not necessarily because they suspect your baby has those conditions at the moment.

Minor Issues

Your newborn may experience more ear infections, sinus infections, respiratory infections, or constipation issues than most babies. Some parents also report a frequent low-level congestion as well, which makes a cool mist humidifier, saline drops, and a nasal aspirator, such as the NoseFrida, helpful products to keep in your home.

Most minor medical issues are truly minor, but you will want to contact your medical provider if the conditions persist or become more severe. You will also want to keep your doctor informed during regular appointments about any areas of concern.

More Complicated Issues

In addition to common newborn issues and minor issues related to Down syndrome, your newborn may experience more complicated health conditions. The American Academy of Pediatrics (AAP) guidelines for the *“Health Supervision of Children with Down Syndrome”* detail conditions and percentages of the population impacted,¹⁴ but we will discuss only some of them based on percentage and newborn status

Hearing issues (approximately 75% of children with Down syndrome). Although some issues may occur when the child is older, newborns should be evaluated for congenital hearing loss with a hearing test. The AAP recommends a brainstem auditory evoked response (BAER) or an otoacoustic emission (OAE). If this was not done in the hospital, ask your pediatrician for a referral. If your pediatrician cannot see your baby’s eardrums because of tiny ear canals common in people with Down syndrome, or if you suspect any hearing issues, your pediatrician will likely refer you to an otolaryngologist, often called an Ear, Nose, and Throat Specialist (ENT), to perform an evaluation or address any problems.

Vision issues (approximately 60% of children with Down syndrome). Although some issues may occur when the child is older, newborns should be evaluated for eye issues within the first six months by a pediatric ophthalmologist. Prior to

14 American Academy of Pediatrics. (2011). Health supervision for children with Down syndrome. *Pediatrics*, 128(2):393.

discharge from the hospital, the physician should check for neonatal cataracts. This is done by the physician looking for a “red reflex” on your baby’s eye exam.

Heart defects (approximately 50% of newborns with Down syndrome). Because heart defects impact about half of babies with this condition, cardiac evaluation and an echocardiogram are recommended for newborns.¹⁵ Experts recommend that even if you already had a reassuring fetal echocardiogram, a postnatal echocardiogram is always needed. See “Learning About Heart Defects” on page 75 for more details.

Infantile spasms (about 5-10% of children with Down syndrome). A small percentage of children may experience seizures, particularly between 5-10 months of age. Prompt treatment can dramatically help. If your child shows symptoms of infantile spasms, like arching, stiffening, or grimacing, record the episode and contact your pediatrician right away. A neurologist can then evaluate your child and develop a treatment plan, usually with diet changes and medication. See [Infantile Spasms and Down Syndrome](#) from the Mass General Hospital Down Syndrome Program.¹⁶

Thyroid issues (about 4-18% of children with Down syndrome). Although only 1% of newborns with Down syndrome have congenital hypothyroidism at birth, children may acquire thyroid issues as they grow. Babies should have a blood test at birth, six months, and every year thereafter. Hypothyroidism is usually treated with daily medication, and thyroid issues can be damaging to cognitive function if left untreated.

Gastrointestinal atresia (12% of children with Down syndrome). Babies with Down syndrome are usually evaluated for gastrointestinal (GI) atresias, as well as other GI issues such as constipation and reflux. See “Understanding Gastrointestinal Issues” on page 73 for more details.

15 See the Cardiology/Down syndrome website at Cincinnati Children’s Hospital (<https://www.cincinnatichildrens.org/patients/child/encyclopedia/defects>) and the Trisomy 21 website at Children’s Hospital of Philadelphia (<http://www.chop.edu/conditions-diseases/trisomy-21-down-syndrome>).

16 See the Infantile Spasms and Down Syndrome handout at Massachusetts General Hospital (<https://www.massgeneral.org/assets/MGH/pdf/children/down-syndrome-infantile-spasms.pdf>).

Transient Myeloproliferative Disorder (TMD) (about 10% of babies with Down syndrome). TMD is a condition where blood cells are not made properly, which can lead to anemia. Each baby needs a Complete Blood Count (CBC) with differential to screen for TMD because TMD increases a child's risk for acute myeloblastic leukemia (AML).¹⁷

LEARNING ABOUT FEEDING ISSUES

Some newborns with Down syndrome have feeding and slow weight gain issues after birth. Causes may be sleepiness, heart or intestinal issues, tongue thrust, weak suck, reflux, or other possibilities. Your baby may eat like a champ right from the start with no problems. However, your baby may have issues with breastfeeding or bottle feeding.

If you wish to breastfeed but encounter challenges, refer to "Breastfeeding" on page 59, read the book *Breastfeeding and Down Syndrome*, and ask to meet with an experienced lactation consultant or other expert.

For bottle feeding, you can consult with an occupational therapist or speech/language pathologist and your pediatrician. They may recommend a specific type of nipple and nipple flow, a feeding schedule, different types/amounts of formula, and tips to prompt the sucking reflex.

Sometimes medical issues may trigger more serious eating issues, and some newborns with Down syndrome may use artificial feeding systems, such as a nasogastric tube ("NG-tube") or a gastrostomy tube ("G-tube"). These systems may be needed only during a hospital stay or for longer. Your provider can share more detailed information if your infant requires an alternative feeding system.

For more details about these artificial feeding systems, please see these resources:

Gastrostomy tube

- [*Cincinnati Children's Hospital: Gastrostomy Tube \(G-Tube\) Home Care*](#)

17 <https://www.massgeneral.org/children/down-syndrome/abnormal-blood-tests-in-children-with-down-syndrome>

-
- [Children’s Hospital of Philadelphia: Gastrostomy Tubes](#)

Nasogastric tube

- [Cincinnati Children’s Hospital: Insertion of Silastic Nasogastric Feeding Tube](#)
- [Children’s Hospital of Philadelphia: Nasogastric \(NG\) Feeding Tube Insertion Video](#)

UNDERSTANDING GASTROINTESTINAL ISSUES

Less Complex Issues

Some newborns with Down syndrome deal with exactly the same issues as other babies, including reflux. Dr. Len Leshin notes that it is not certain that babies with Down syndrome have gastroesophageal reflux (GER) more frequently than other babies, but that increased frequency makes sense due to the lower muscle tone. While most babies spit up, your baby may need treatment if showing signs of distress or experiencing health issues connected to spitting up. Generally, a baby with GER will spit up more forcefully—even vomit—at every feeding. Even if the liquid does not come all the way up, symptoms like choking, gagging, prolonged fussiness, or other signs of distress in your baby should mean a trip to the pediatrician or emergency room.

For a complete explanation, see [Dr. Leshin’s article on “Gastroesophageal Reflux \(GER\)”](#).

Dr. Leshin also addresses constipation, which occurs more often in babies with Down syndrome because of low muscle tone and decreased motor activity. Your pediatrician may instruct you to use a stool softening product in your baby’s bottle or a suppository. In addition, pediatricians may simply recommend natural remedies like prune juice with pulp. Dr. Leshin advises using these products with the instruction and dosage recommendation of a doctor. Keep your doctor informed about the existence and extent of constipation because persistent constipation can indicate more serious issues such as a rectal problems, a condition called Hirschsprung disease (treatable with surgery), or hypothyroidism (treatable with medication).

For more details, see [Dr. Leshin’s article on “Constipation.”](#)

More Complex Issues¹⁸

Some babies with Down syndrome experience more significant gastrointestinal issues, such as Hirschsprung's disease or duodenal atresia. As explained by Cincinnati Children's Hospital, intestinal atresia has a positive long-term prognosis with proper medical care. However, it can present challenges in the newborn stage as parents face the prospect of newborn surgery. An atresia is a blockage, which can happen at various places along the intestinal route, while a stenosis is a partial blockage. These require surgical intervention very early on. If suspected at birth (by physical exam or symptoms such as vomiting or distended abdomen), you can expect a series of tests (e.g., X-ray, upper and lower GI series, ultrasound) to confirm the diagnosis and identify the severity of the condition.

For an explanation of the different types of atresia and stenosis, an explanation of the surgical procedures, and other useful details, refer to the intestinal atresia and stenosis website at [Cincinnati Children's Hospital](#).

Family Stories

From Megan Landmeier, describing how her daughter was born with a heart defect and duodenal atresia:

After a Down syndrome diagnosis and a heart defect, the "double bubble" (duodenal atresia) was the final, overwhelming, "not something else!" She was born via c-section after an induction.

First, let me say that the feeding tube was a big fear of mine, but Ellie never had one. She did have a nose tube for drainage. After the nose tube came out, Ellie began four or five days of 5 mL of milk every three hours. She slowly worked up to 70 mL by bottle. At three months, Ellie decided she was cool with nursing. At four months, she took half her feeds by bottle (formula) and nursed the other half. She stayed on that pattern until about 7-8 months, when she was partially weaned, largely for mom's sake. She switched to formula only at ten months, but moved to solids fully by 13 months. Now as a pre-schooler, she is a champion eater who loves curry, burgers, pasta, and cookies."

¹⁸See the Intestinal Atresia and Stenosis website at Cincinnati Children's Hospital (<http://www.cincinnatichildrens.org/health/info/abdomen/diagnose/obstructions.htm>)

LEARNING ABOUT HEART DEFECTS¹⁹

An estimated 50% of children with Down syndrome also have heart issues. Most new parents learn of a baby's heart condition through an echocardiogram. Many issues can be treated with only monitoring, and many resolve on their own or with medication. Others can be treated with various procedures, and some may need open-heart surgery. The vast majority of issues are resolvable. With medical advancements in recent years, heart issues are less and less of an obstacle.

Monitoring. With many heart defects, holes seen in utero or in the newborn period may close on their own. The cardiologist usually requests follow-up appointments to monitor the defect.

Catheterization Procedure. In this procedure, a medical provider inserts a catheter through a vein or artery to evaluate the heart or to fix a defect. Many heart defects are repairable through this procedure, rather than open-heart surgery, and usually only require an overnight hospital stay.

Heart Surgery. Some heart defects are repairable only through heart surgery. Recovery times vary depending on the hospital or the child. Babies may leave the hospital as early as three days after open-heart surgery, but most parents prepare mentally for a week-long stay. Some babies may stay longer if complications arise.

If you bring your baby home for months before open-heart surgery, your cardiologist will monitor your baby's weight and health with regular visits. Routine visits will include a physical exam and questions about the baby's sleep and eating habits. Depending on baby's situation, your cardiologist may conduct an EKG, perform an echocardiogram, or prescribe medications at any visit. The timing of surgery depends on many factors, including weight and signs of heart

¹⁹See the Cardiology/Down syndrome website at Cincinnati Children's Hospital (<https://www.cincinnatichildrens.org/patients/child/encyclopedia/defects>); the Open Heart Surgery page at Cincinnati Children's Hospital (<http://www.cincinnatichildrens.org/health/heart-encyclopedia/treat/surg/open.htm>); the Cardiac Treatment Options page at Cincinnati Children's Hospital (<http://www.cincinnatichildrens.org/health/heart-encyclopedia/treat/default.htm>); the Trisomy 21 website at Children's Hospital of Philadelphia (<http://www.chop.edu/conditions-diseases/trisomy-21-down-syndrome>); and "The Heart Book" by the Cardiac Center at Children's Hospital of Philadelphia (<http://www.chop.edu/centers-programs/cardiac-center>)

issues (e.g., excessive sleepiness, difficulty eating, blue skin tone). A pre-surgery visit may involve a physical exam, blood work, echocardiogram, and an X-ray.

If your doctor has already identified a heart defect that may require surgery, you can also contact your local Down syndrome organization to connect with other parents whose babies experienced similar issues. Experienced parents may also offer tips to help prepare for surgery and share more information about your local hospital and services. In addition, you can try to boost your baby's immune system before and after surgery by providing breastmilk for the recommended time.

If a child has more complex health issues, you might seek additional consultation at a nationally-recognized children's hospital. A larger hospital may have more experience with complex issues, so it could be helpful to get further input.

Please see the following resources for new parents dealing with cardiac issues:

- [CongenitalHeartDefects.com](https://www.congenitalheartdefects.com)
- [Congenital Heart Information Network](https://www.congenitalheartinformationnetwork.org)
- [Down's Heart Group \[UK\]](https://www.downsheartgroup.org)
- [Baby Center "Babies and Children with Heart Conditions" discussion board](https://www.babycenter.com/discussion-board/babies-and-children-with-heart-conditions)
- [Cincinnati Children's Hospital explaining AVSD \(the most common heart defect in people with Down syndrome\)](https://www.cincinnatichildrens.org/health-care/heart-conditions)

Family Stories

From Melissa Stoltz, talking about her daughter's AVSD/CAVC:

We learned about Rowenna's heart condition 36 hours after she was born. She had a Complete Atrioventricular Canal (also known as a CAVC or AVSD). We spent two weeks in the NICU while doctors monitored Rowenna's heart. It is so hard to think about now—we were waiting for her to go into heart failure. Looking at my tiny bundle in her isolette and knowing her heart was working too hard was very difficult. In another way, it helped me to work through the Down syndrome diagnosis. There was definitely a feeling of "Well, who cares about this Down syndrome thing? My baby needs heart surgery."

While in the NICU we also worked with Rowenna on eating. We tried to get her to nurse, but she would get so tired at her feedings that we made the extremely difficult decision to switch to a bottle. At the time, it felt like one more thing being taken away from me, but I know now it was a good decision for my daughter. When we left the NICU, she was taking some milk by mouth and some through an NG-tube.

Over the next three months, we lived as normal a life as possible. Our cardiologist and pediatrician both stressed the importance of getting out of the house and remembering that she was just a baby first and foremost. We went shopping, visited county fairs and festivals, and even went camping with family. We were vigilant about hand-washing and using hand sanitizer. It felt good to be out and about!

Rowenna was a pretty typical baby. She smiled and babbled and tried out all her physical skills—reaching for toys, tummy time, trying to roll. She loved to snuggle. Aside from her NG-tube, there weren't a lot of signs that something was wrong on the inside.

When Rowenna was about three months old, her heart condition really began to take its toll. She became very pale and tired. She stopped enjoying tummy time and began to sleep almost constantly. She also stopped eating by mouth. Her cardiologist decided it was time for surgery.

When we got the call with our surgery date, I completely lost it. I cried all afternoon. It felt so real. I would have to hand my baby over to the doctors, and I would have no control over what happened next. We were told to stay home and keep her as germ-free as possible.

Two days before surgery, we met her surgeon. He immediately put us at ease. He had obviously carefully reviewed Rowenna's case and spoke to us about the specifics that pertained to her. The night before surgery I sat up and watched her sleep.

The morning of surgery, we met the surgical team and went over the procedure again. I didn't cry. I felt like I wanted Rowenna to see me smiling and calm. The doctor carried Rowenna in her arms into the OR, and, for some reason, that made me feel so good. My baby was snuggled right until she went under.

That was the longest day of my life. Every hour a nurse would update us in the waiting room. After surgery, they wheeled Rowenna into a hallway on the way to her ICU room, and we were able to get a quick peek at her. She was already awake and looking around!

Rowenna recovered well. Now, you would never know Rowenna ever had a heart condition (unless you see her scar!). She is perky and pink and plump. She is absolutely gorgeous. The heart condition was scary, but I found a great deal of peace in talking to other "heart moms" and having doctors who were so very supportive of our family. Nothing could have made me stop worrying before her surgery, but it helped to know we weren't alone!

See [gardenofmyheart.com](https://www.gardenofmyheart.com) to read more of Melissa's story.

COPING WITH SURGERY OR A NICU STAY

While many babies go home without a NICU stay or surgery, others may spend a few days or weeks in the NICU. Complications, such as prematurity, may require an extended stay. The NICU or surgery may be stressful for parents, especially mothers whose hormones are adjusting after delivery and who may be in physical discomfort.

With beeping monitors and people around constantly, parents might feel stressed. If your baby needs to stay in the NICU, you might want to take some time to collect your thoughts and make arrangements so that the hospital stay is as tolerable as possible.

Some Practical Tips

1. If you want support from family and friends, make a plan for how you want to update them about your child's condition without needing to contact everyone individually. You may want to use a website or app like Caringbridge, or you might want to use social media accounts or email lists.
2. You may want to recruit extended family or friends to help with your other children. Other loved ones may be willing to help with meals and chores.

Lotsahelpinghands.com or SignUpGenius.com are other helpful online resources to explore if you anticipate needing meals or childcare during the hospital stay. These websites allow volunteers to sign up on a closed community calendar and receive email reminders.

Note: We suggest appointing a captain to be your administrator of the site. Your captain can coordinate logistics so you can focus on your baby.

3. Pack or have set aside at home:
 - a journal, camera, and book for reading
 - loose, comfortable clothing or comfortable pajamas for you
 - personal hygiene products
 - healthy snacks
 - a list of your usernames and passwords for online support
 - any necessary chargers for your technology devices
 - also consider downloading any movies, apps, or books you may want on your device

Note: Some hospitals do not allow you to use cellular service that may interfere with medical equipment, but many hospitals do have free Wifi that you can use to communicate instead.

4. If you are breastfeeding/pumping, consider the following:
 - Take literature with you on nursing babies with Down syndrome. See “Preparing for Breastfeeding” on page 73 and [*Breastfeeding & Down Syndrome: A Comprehensive Guide for Mothers and Medical Professionals*](#) edited by Ella Gray Cullen.
 - Ask hospital staff about pumping accommodations: Do they have a pumping room? A pump?
 - Ask if the hospital has a lactation consultant at the hospital who is familiar with Down syndrome and the health issues your baby may face. Meet with this consultant as early as possible so she can help guide you and help interact with the staff if necessary.
 - Ask about breastfeeding policies with babies in the hospital.
5. Have a notebook for medical and medical care provider information or maintain a file on your device. Write the names and titles of all medical care providers, the information they give you, and questions you may have.
6. Remember to take photos during your hospital stay. Some people like to take photos of baby’s first bath, friends and family who come to the hospital to visit, and baby’s first outfit. In addition, some people use photos, along with information, to keep loved ones updated. Others are more private, especially when medical issues are involved. Even if you don’t share the more vulnerable photos, your child may wish to see them in the future.
7. Ask questions:
 - What are the visitation rules for parents, grandparents, siblings, and others?
 - Are there rooms for parents available on site, or lockers or other accommodations?
 - Does the hospital have accommodations like a Ronald McDonald house or discounts at area hotels for longer hospital stays?
 - Is there parent support on site, such as a family center or Down Syndrome Clinic?
 - Is there an occupational therapist on site to work with your baby?

-
8. For babies undergoing surgery, think about the following *before* the procedure:
- For older babies, bring toys with links to hook to the crib.
 - Ask about the procedures for you and your family to donate blood if you wish to do so.
 - Bring clothing with snaps down the front.
9. For babies undergoing surgery, think about the following *after* the procedure:
- Remember that you will have to lift the baby by scooping under the back rather than lifting under the armpits.
 - Ask how long you have to wait before resuming therapy.
 - Ask how long you have to avoid crowds because of possible germ exposure.
 - Ask your doctor about follow-up care and removal of stitches.

Note: Do not be afraid to request the most experienced medical professional for your baby, whether for a blood draw or a more complicated procedure.

Family Stories

From Stephanie Meredith, talking about her son's stay in the NICU for ten days:

Because Andy was my first baby and the diagnosis was a surprise at birth, I was terribly heartbroken that he had complications with an enlarged liver, low platelet count, and difficulty feeding that required him to stay in the NICU. I remember begging not to be released from the hospital and collapsing onto the bed in a heap when I had to go home without my baby. It was probably one of the most agonizing cries of my life. Ten days doesn't seem like very long in retrospect, but time seemed to stand still back then.

Fortunately, the hospital had an experienced mom on staff to provide parent support, and she brought me information about Down syndrome and pictures of her son right away. The hospital also had a room in the NICU just for parents who wanted to stay overnight with their baby. It was a painful transition, but I started to feel excited and hopeful again as the occupational therapist helped me to use the pump at the hospital, some friends and family started visiting, we decorated the isolette and made playlists for him, and I was able to hold him with skin-to-skin contact. Then it took me another month after he was released to realize I didn't have

to record every movement on a chart like they did in the NICU!"

From Megan, discussing her daughter's stay in the NICU with a heart defect and duodenal atresia:

While most of our nurses were amazing, the NICU experience is inherently stressful. We opted to come home to sleep, but I spent the majority of each day in Ellie's room. She came home when she was three weeks old. I would recommend asking plenty of questions, developing good relationships with the nurses, helping with your child's care, and, of equal importance, taking care of yourself while your child is in the NICU.

FINDING MEDICAL RESOURCES

For more information on health issues in the early life of a child with Down syndrome, see the following:

- [*AAP Health Supervision of Children with Down Syndrome by the Committee on Genetics in Pediatrics*](#), including a health care checklist at each age
- [*NDSS Healthcare Associated Conditions*](#)
- [*Growth Charts for Children with Down Syndrome by Zemel, et al.*](#)

It may be useful to start a binder or digital file for medical information, where you can keep important records, test results, and questions for your pediatrician. Consider printing the AAP health care guidelines with the checklist for medical recommendations at each age.

For more information on developmental milestones beyond just health issues, see "What Kind of Developmental Progress Can I Expect My Baby to Make?" on page 90.

[*Related Articles on DownSyndromePregnancy.org*](#)

You can visit DownSyndromePregnancy.org for articles such as, "[*Organization and Preparedness 101*](#)" and "[*Calling All Heart Moms.*](#)"

SHOULD I BANK MY BABY'S CORD BLOOD?

Some parents want to bank their baby's cord blood with hopes of possibly treating future medical conditions, such as cancer and diabetes. While people with

Down syndrome have lower chances for developing certain tumor cancers,²⁰ they do have 1 in 100 odds for developing leukemia.²¹

While some parents bank cord blood to possibly treat leukemia if it occurs in later years, Dr. Beverly Lang, pediatric oncologist at Children's Hospital of Philadelphia (CHOP), advises that the cord blood of a child with Down syndrome would not be used to treat leukemia for either that child or a sibling.

Scientists believe original cells that cause leukemia in a child with Down syndrome might be present in the cord blood. So, giving cord blood might just be giving back the precursor cells for leukemia. For this reason, cord blood from babies with Down syndrome cannot be used if they go on to develop leukemia later on in life. However, banking the cord blood from your pregnancies with siblings could be beneficial if your child with Down syndrome develops leukemia, which occurs in less than 1% of these children.

If you wish to bank your baby's cord blood for other purposes that could benefit your baby, consider discussing any potential benefits with your medical care provider.

In addition, you may want to consider the possibility of banking your baby's cord blood for later use in research that may benefit people with Down syndrome. Researchers have made great strides in discovering the biological causes for some of the issues associated with Down syndrome. Biobanks will be an important part of future research, and cord blood can be a good source for tissue samples.

If you wish to donate your cord blood, you can ask your healthcare provider about options in your area.

To learn about Down syndrome research, see "National Down Syndrome Research Organizations" on page 120.

20 Satgé D, Bénard J. (2008). Carcinogenesis in Down syndrome: What can be learned from trisomy 21? *Semin Cancer Biol*, 18(5):365-371.

21 See Blood Disorders in Children with Down's Syndrome: Overview and Update from the Down Syndrome Medical Interest Group (<https://www.dsmig.org.uk/information-resources/by-topic/blood-disorders/>)



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FINDING SERVICES AND UNDERSTANDING DEVELOPMENT

After receiving a diagnosis, many parents start to wonder about the nuts and bolts of providing for their child. Questions range from “How will this impact my health insurance?” to “What kinds of services do children with Down syndrome need?”

The good news is that many different services and programs are available for your child, but the challenge can be finding those services because they vary widely and have different names in different places. A hospital social worker can be an excellent resource to help connect you and explain all the social service options available. Others who can guide you through the maze of services in your area include an Early Intervention (EI) service coordinator, a pediatrician, a local Down syndrome organization, a genetics clinic, or the local health department.

You may want to start a research file for this information. It makes contacting these organizations and keeping track of your communications much easier as time goes on. Below is a general explanation of these different services so you can understand some of the basic jargon and acronyms and where to begin.

HOW DO I MAKE SURE MY CHILD IS COVERED BY HEALTH INSURANCE?

Private Health Insurance

Private group health insurance plans, including COBRA policies, are required to cover your child with Down syndrome—just like any other child added to the plan. If you have a private family insurance plan through your employer, it is likely you have an adequate group health plan that will cover your child. However, **private individual health insurance plans** generally deny coverage for children with Down syndrome because they consider it a pre-existing condition. A pre-existing condition is a health condition that has been diagnosed before the first day of coverage on a new health plan. Health care plans under the Affordable Care Act are prevented from denying policies to individuals with any pre-existing condition; however, the protections in place are currently uncertain and subject to change. You will need to check with an insurance broker with experience handling policies for children with disabilities or a health advocacy organization in your state to know the current status of the law and what options are available to you.

Children's Health Insurance Program (CHIP)

Another health insurance option available to children with Down syndrome, as well as all qualifying children, is health coverage through a state Children's Health Insurance Program (CHIP). CHIP can provide free or sliding-scale fee health insurance for children who are not covered by private health insurance; however, eligibility for CHIP can also depend on your income. You can find out more information by referring to [Insure Kids Now](#).

A variety of state agencies provide support to families of children with Down syndrome—ranging from rural clinics to monthly consultations.

Medicaid

Medicaid is a health care program that supports many children and adults with disabilities across the nation. As a federal program administered by individual states, there is some variation in procedures, application processes, and eligibility for Medicaid. Sometimes Medicaid is automatic if a child qualifies based on

family income or if your child receives Supplemental Security Income (SSI), but other times states will require that you apply separately.

Some states will provide Medicaid to a child with Down syndrome regardless of income. For example, some states have what is known as a **“Katie Beckett Waiver”** for children with disabilities, which allows them to qualify for Medicaid based on disability, not income. The term “waiver” means the state has waived some of the federal Medical requirements, which can include a review of a family’s income and assets. This Medicaid policy can be used as a primary or secondary policy to offset costs sometimes not covered by primary insurance, such as therapies and certain pieces of equipment.

Other states have specific developmental disability Medicaid programs that determine eligibility based on the needs of each child. However, states often have limited slots available for those programs and may have a waiting list.

A Medicaid waiver can provide the support of additional health care coverage, but it can also include a package of services that are not necessarily provided for under private insurance or typical Medicaid. These services may include such things as respite care, assistance with travel expenses, or equipment and supplies. States often have a limited number of slots available and waiting lists for those slots.

For a general overview, see [Social Security Online: Benefits for Children with Disabilities](#).

Family Stories

Various stories of parents describing their experiences with insurance:

When my baby was born in Utah, I worked for a technology firm, and my son was covered under my group health insurance just like any other child. Then he also received speech and occupational therapy from the state Early Intervention program, and they helped us teach him to suck properly, eat, and roll over.

We had a really rough year after losing a job and having two children, including one with Down syndrome, while living in New York. We were able to get Medicaid as a family with a low income. This was a temporary situation that lasted for a year until we were able to get our feet back on the ground, but we were so grateful Medicaid could cover the immediate medical needs of our children. We also

received a stipend for respite care (child care for children with disabilities) and Early Intervention services through the state from a speech pathologist and occupational therapist who came to our home every week.

As a self-employed family with three children in Georgia, we used a family policy through the Health Insurance Marketplace. Because this policy was part of the Affordable Care Act, they did not deny our son based on Down syndrome as a pre-existing condition. We also used a Katie Beckett Medicaid Deeming Waiver to get Medicaid as a secondary policy for services that weren't covered by traditional insurance, like speech and physical therapy.

HOW DO I SUPPORT A CHILD WITH DOWN SYNDROME ON A MODEST INCOME?

Research shows that families do have higher costs when raising a child with Down syndrome, but those costs can vary widely for different families based on the needs of their children at different ages. The highest medical costs usually come in the first year when surgeries are more common. On average, parents of children with Down syndrome pay an additional \$84 per month for out-of-pocket medical expenses when costs are drawn out over 18 years.²² There are also local and national resources available to help families address financial needs.

Supplemental Security Income (SSI)

Families of a child with Down syndrome might qualify for SSI if their income is below a certain level. SSI is a monthly payment to your child. While technically you must apply and wait for a determination that your child is “disabled,” a diagnosis of Down syndrome usually meets the criteria.

Generally, applicants need to provide records such as a birth certificate, social security number, and medical records including the karyotype (the genetic test confirming a diagnosis). You will also need to provide documentation about your household income, which cannot exceed a certain amount — usually

22 Kageleiry A, Samuelson D, Duh MS, Lefebvre P, Campbell J, Skotko BG. (2017). Out-of-pocket medical costs and third-party healthcare costs for children with Down syndrome. *American Journal of Medical Genetics Part A*, 173(3):627-637.

the federal poverty level. Your child's SSI amount may vary from state to state because some states supplement the federal amount.

Related Article on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for the article: "[Possible SSI Benefits When Your Baby Has Down Syndrome.](#)"

HOW DO I MAKE SURE MY BABY LEARNS AND GROWS?

Early Intervention (EI), is a program that is provided in all states and US territories. Focusing on supporting the growth and development of infants and toddlers with disabilities from birth to age 3, the authority for this program comes from the Individuals with Disabilities Education Act (IDEA). EI can vary from state to state, and in some ways from county to county. In most cases, staff will come to your home (or your child's day care setting) to provide services to your child.

The primary purpose is to teach you ways to help your child learn and grow doing what they love to do best during their day. Sometimes there are EI therapy centers where parents can bring their children. EI services should be motivating for you and your child. Every child in EI has an Individual Family Service Plan (IFSP) which focuses on your child's growth, and also how your family is doing. In addition, the IFSP can focus on outcomes that provide you with support, information, and emotional support.

Some families choose to get started with EI right away to help with things like feeding and rolling over. Other families choose to wait until medical issues are resolved or until they have adjusted to life with a new baby. All of these approaches are just fine, but you'll want to know where to access EI services when you're ready.

The services and the professional background of your family's EI staff may vary depending on the structure and policies of your local EI, what your child needs, and what you seek for your child. IDEA recognizes 17 different types of services. In the three years with EI, you may add or drop services depending on your child and/or family's needs.

Cost/Parental Contribution: Some states have EI programs that provide services at no cost to parents. Other states require some type of parental contribution,

usually taking into account family income and family size. You may be asked whether or not you will allow your child's public and/or private health insurance to be used for services. IDEA assures you have the right to make a decision about this allowance.

Your local EI: Many states have developed unique names for the EI programs. In order to get a general understanding of the way EI operates in your area and what it's called, you should contact your EI provider or review its website. You can find a list of many EI programs at the [Center for Parent Information and Resources Library](#) by looking up the Parent Center in your state and exploring the resources or services. You may also contact your pediatrician, ask your birthing facility, check your local library, or contact the local health department. Local parents and Down syndrome support organizations can give more unofficial and sometimes more insightful tips about the local EI provider.

First steps: Making the phone call is the first step. The hospital may contact EI through official channels, or you may contact them yourself from the hospital or once you return home. The EI office sets up an initial meeting at your home where you fill out general forms with your family, income, and medical information. Parents report different "start" times for EI that depend on various factors, but IDEA requires your IFSP meeting must be held within 45 days after a referral is made. Timely initiation of services is monitored by every state and is publicly reported. Very early visits may focus on difficulties with nursing or bottle-feeding, administering medications (if needed) to a baby so young, or proper ways to hold and support a newborn with Down syndrome, for example. The focus of EI services grows and changes with your child.

Early Intervention serves many different children, some of whom have unexpected developmental delays that require an evaluation process to determine eligibility for services. Most states have provisions that make children with Down syndrome automatically eligible for EI. Some states may require that children need to be determined as "eligible" for services based on specific delays. For example, your child may start with physical therapy, and then later may be required to participate in an evaluation process for specific services such as speech therapy.

A Team Approach: EI is based on a team approach, and you as parents or caregivers are part of that team. It can be disconcerting for parents to be asked at early meetings, "What goals for your child do you have for the next six months?" or "What do you think about starting with physical therapy one hour every other

week?" In the beginning, we may want to respond, "You tell me. You're the experts. I don't know anything." After all, how can we be expected to know what our babies should be doing in a few months?

While this can be a bit strange in the beginning, as months go by, you will get a better sense of your child, her personality, strengths, and weaknesses. You'll soon realize that your knowledge of your child exceeds that of the professional members on your team. You spend the most time with your child, and you want what is best. So although this role of knowledgeable team member may seem uncomfortable at first, rest assured you'll grow into it. Eventually you'll find yourself adding your observations to meetings, sharing what progress you would like to see, and, in some cases, advocating for services you feel your child needs. You will become an active participant during the regular team meetings to review and update your child's IFSP.

Your role: As parent or caregiver, your role in your child's development is central. EI and any other therapy services that you engage in can support you and your child by providing expert guidance and modeling effective approaches. However, your child's development truly depends on everyday interactions, play, and opportunities for learning—not just the support your child receives from professionals during therapy sessions. You should strive to develop and maintain a positive, collaborative partnership with the professionals who support your child, observing modeled interventions, reporting new developments to the staff, and learning strategies to engage with your child during your daily routine. Actively engage with your child and staff when you are with them, ask questions, learn new skills, and find ways to include other members of your family in the new information you are learning.

You can request written reports of each session to keep for your own review and share with other therapists to ensure consistent care. You will also participate in meetings where the team records progress and sets new goals.

EI is very much a group effort, and service providers are usually flexible in adapting to the needs and schedule of each family.

Other Services Beyond Early Intervention

Some parents choose to seek out additional therapeutic interventions for their child beyond the services contained in their state's EI program. Typically these services are ordered by your pediatrician and paid for through your private

insurance and your child's Medicaid. These services are generally provided in an environment such as an outpatient clinic or pediatric therapy center. It is good to have a release of information signed between these services and your EI staff so that they can coordinate goals and interventions to help your child learn and grow.

WHAT KIND OF DEVELOPMENTAL PROGRESS CAN I EXPECT MY BABY TO MAKE?

Whether you are an experienced parent or not, most people have a basic understanding of milestones. We know babies smile, laugh, babble, roll over, sit up, stand, walk, run, and talk. Children with Down syndrome usually accomplish these same milestones in the same order as other children, but it generally takes longer.²³ You can view the [Motor Development & Self-Help Skills Milestones chart](#) to see the average age when children with Down syndrome accomplish their developmental milestones. Another resource is the [What do we know about the movement abilities of children with Down syndrome?](#) available at Down Syndrome Education Online, which includes an overview of the development of babies and infants from birth to five years by Sue Buckley and Ben Sacks.

In observing and assisting your child's early development, you will be keenly aware of and celebrate the small steps leading up to each major goal. Crawling, for example, starts with many tiny stages, such as tummy time, head lifting, an army crawl, and perhaps a bear crawl. These smaller steps are described as goals, along with the larger milestones, and therapists demonstrate the play-based "exercises" you can do to help meet these goals.

During the early years, you might feel pressure to do all the therapy, read all the books, and do all the exercises to make sure your child meets their milestones. But remember to pace yourself and also remember that your baby is a baby first. Therapy is a helpful supplement to achieve those milestones, but do not allow that pressure to eclipse those opportunities to enjoy your child and take care of yourself. Most kids with Down syndrome turn out just fine even if they watch TV sometimes while you catch up on emails and even if they eat goldfish from between the couch cushions every now and then.

23 <https://www.massgeneral.org/news/press-release/mghfc-study-details-development-of-functional-skills-in-persons-with-down-syndrome>

WHAT KINDS OF PROFESSIONALS CAN HELP MY CHILD AND ME?

El programs vary in both the selection and availability of services. You may have a “jack of all trades” service provider or developmental specialist, or you may have a variety of professionals with different specialties. You may see a service provider once a month, every other week, once a week, or multiple times a week depending on several factors. If you’re unsure how much therapy your child should receive, you can consult with a developmental pediatrician or other professional at a Down syndrome specialty clinic to evaluate your child and review his or her needs. Some simple explanations of potential professionals a child may see include the following:

Physical Therapist (PT): Focusing on gross motor skills and overall strength. Larger milestones may include rolling over, sitting, crawling, or walking.

Occupational Therapist (OT): Focusing on fine motor skills, including finger and hand dexterity and strength. Examples include switching objects hand to hand, putting things “in” and “out,” beading, and holding a pencil.

Speech/Language Pathologist (SLP): Supporting the development of pre-speech and feeding skills, as well as listening and speech production skills from early babble to whole words, and the development of clear speech, vocabulary, and grammar.

Sign Language/Cued Speech Teacher: Teaching children and families some sign language or gestures as a communication tool and transition to speech.

Some children may require little use of sign language, while others may experience more delay and find more extensive use of sign language useful. Some parents worry that introducing sign language may delay speech, but research shows that children who learn signs actually have stronger speech skills.²⁴

Feeding Specialist: Focusing on feeding issues related to medical or sensory issues.

24 Thompson RH, Cotnoir-Bichelman NM, McKerchar PM, Tate TL, Dancho KA. Enhancing early communication through infant sign training. *J Appl Behav Anal.* 2007;40(1):15-23. doi:10.1901/jaba.2007.23-06

Developmental Interventionist (teacher) or Early Childhood Specialist: Serving young children with disabilities using a variety of educational techniques and/or play therapy.

Other possible options include music, behavior (for positive behavior supports), aquatic, equestrian (with horses), and play therapy.

Service professionals work together toward developing your child's physical, cognitive, speech, and social skills. In infancy, the developmental areas overlap significantly, and as your child develops, these skills become dependent on each other. All therapists may try to encourage speech and basic sign language or gestures appropriate for a toddler, and most professionals have a basic understanding of issues that involve muscle tone, motor planning, and cognition.

WHY DO PROFESSIONALS RECOMMEND USING SIGN LANGUAGE WITH BABIES?

Because speech is usually delayed in children with Down syndrome, sign language can be an important bridge in developing language and communication skills. Children with Down syndrome typically understand – and wish to express more – than they can easily say. Sign language can facilitate communication for children while their speech develops. For example, most children with Down syndrome can recognize a horse before they can say the word “horse.” Sign language allows children to communicate their thoughts, wants, and needs even if they can't speak yet or if their speech isn't very clear. Some children may only use sign language for a short time as they strengthen their verbal skills. Others may experience a greater delay and may need to use sign language for a longer time.²⁵

Some families worry that teaching sign language might prevent their children from speaking words, but research shows that children who sign actually have better language skills.²⁶ This is because they are learning to “practice” language.

25 Thompson RH, Cotnoir-Bichelman NM, McKerchar PM, Tate TL, Dancho KA. Enhancing early communication through infant sign training. *J Appl Behav Anal.* 2007;40(1):15-23. doi:10.1901/jaba.2007.23-06

26 Goodwyn, S., Acredolo, L., Brown, C. (2000). Impact of symbolic gesturing on early language development, *Journal of Nonverbal Behavior*, 24:81-103.

Signing can also be helpful because some children with Down syndrome may have hearing loss or may not be very verbal. EI providers and speech/language pathologists often can help you and your child learn signs. Fundamentally, most parents find signing to be fun as they learn a new skill and find out what their baby is thinking, and signing can also prevent frustration as children can communicate their wants and needs more clearly.

THERAPY/SIGN LANGUAGE RESOURCES

For more information on therapy and sign language resources, see the following:

- *Early Communication Skills for Children with Down Syndrome: A Guide For Parents and Professionals* by Libby Kumin, Ph.D., CCC-SLP
- *Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals* by Maryanne Bruni, BScOT (Reg)
- *Gross Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals* by Patricia C. Winders, P.T.
- *SigningTime*
- *Tiny Signs*

As you start your EI journey, you may also want to start a therapy binder or digital file, where you can keep contact information for EI providers, evaluation results, and therapy notes.

Family Stories

From Nancy Iannone, describing how her daughter used signs to communicate:

Gabby could sign the word, "shoe," when she could only make the "s" sound verbally. Signing was incredibly helpful in allowing us to understand what she was thinking and helping us to then encourage her to say the whole word as she developed those skills. We always used sign as a tool to encourage speech.

It was so exciting to know what she wanted long before her speech was articulate enough to understand. At 15 years of age, Gabby's speech is among her greatest strengths, but early on we just did not know if her expressive skills and articulation would allow us to easily understand her. It was a comfort to know that sign language was an aid to speech development, but would also have been her primary communication if her verbal skills did not develop as well as we hoped.

Related Articles on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for the articles: *“Learning to Teach Baby”* and *“The Mediocre Mom’s Guide to Raising a Child with Down Syndrome (Or Any Kid for That Matter).”*

WHAT CAN I DO TO HELP MY BABY LEARN AT HOME?

By Sheryl Friess Zellis, Occupational Therapist

Your baby with Down syndrome, just like any baby, has multiple sensory systems waiting to be stimulated. Many simple and even fun activities can be part of your bonding experience and can positively contribute to the growth and development of your baby.

Each interaction is an opportunity to stimulate the senses. At the same time, you can learn what makes your baby happy and comfortable.

Activities to Provide Light and Deep Touch

- Gentle massage to baby’s arms, legs, trunk, and back. You can do this while rubbing moisturizer on your baby after a bath or just to soothe.
- Gently rub a variety of soft textured materials on your baby’s arms, legs, back, trunk, and cheeks. A soft wash cloth feels very different to a baby than a piece of cotton or a thick towel.

Activities that Provide Auditory/Hearing Stimulation

- Play a variety of different types of music from classical to children’s tunes.
- Sing, sing, and sing to your baby who loves your voice! Make it high, low, animated, or quiet. (Look at your baby’s face and move your head so baby will follow your voice.)

Activities that Are Pleasing Visually Through Baby’s Eyes

- When baby is lying down face up, place your face several inches away. Move from one side to the other while making eye contact to encourage baby to follow your movement.

-
- Lay baby on the side or belly, and prop black and white bold pictures of simple faces or shapes to look at. Be surprised when baby “studies” them!
 - Make different faces close to baby’s face to entertain baby. Eventually, you may even get a smile back!

Activities to Stimulate Tolerance to Textures Around and in the Mouth

- Gently rub various soft textured materials (washcloth, cotton, blanket), on the cheeks, lips, and chin.
- Place gentle kisses around the mouth, cheeks, and neck.
- Gently massage moisturizer on baby’s cheeks and chin.
- Rub your clean finger (with closely clipped finger nails), over baby’s lips, inside the mouth on the gums, and inner cheeks.

In summary, any of these activities will encourage wonderful responses from your baby and make you look forward to diaper time! Choose a few each time and enjoy your baby!



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LOOKING TO THE FUTURE

Improved opportunities for education, recreation, and employment mean that people with Down syndrome are consistently enjoying more enriching lives. We expect people with Down syndrome to be included as integral parts of our communities and schools, and we know they make meaningful contributions to the world around them. Glimpses into the lives of people with Down syndrome show that they are individuals with unique strengths, interests, challenges, and opportunities.

LOOKING TO THE FUTURE AS A PARENT

Marriage

Some parents worry about the impact of a child with a diagnosis on their marriage. The good news is that one study shows that the overall divorce rate is actually lower for the parents of children with Down syndrome.²⁷ Parenting a child with Down syndrome can require a couple to navigate some more complex is-

27 Urbano, R., & Hodapp R. (2007). Divorce in Families of Children With Down Syndrome: A Population-Based Study. *American Journal on Mental Retardation*, 112:261-274.

sues when caring for their child, but the teamwork can also bring some couples closer together and help broaden their perspective on priorities. And yet, even though the divorce rate is lower on average for parents of children with Down syndrome, you can also find wonderful support for single parents in the Down syndrome community as well.

Family Stories:

I was 23 years-old, and my husband was 24, when our first child was born with Down syndrome. I truly realized how much I appreciated my husband when I saw him cradling Andy beside the bassinet in the NICU. My husband was at an age where so many of his peers were still care-free in college, and he never flinched for an instant in standing by my side and in adoring Andy. I think that experience solidified our commitment to each other and our family. Now that doesn't mean life has always been easy—we still argue about finances, parenting strategies, and how many soda cans he leaves around the house, but having a child with Down syndrome put what was really important into clear focus for both of us very early on. What matters most is advocating for all our children as a team, making time for each other as a couple, and supporting each other in accomplishing our goals.
—Stephanie

Employment

Sometimes parents worry about whether they will be able to return to work after having a baby with Down syndrome. While your new baby may require more of your time in the beginning, particularly if health issues need to be treated, most parents of children with Down syndrome do return to work and enjoy careers in a wide range of fields. Parents of children with Down syndrome are teachers, engineers, actors, non-profit directors, business owners, and so much more. Some families even find themselves following new career paths after the birth of their baby because they want to be more involved in the advocacy world, and many parents continue down other meaningful career tracks.

In many homes, both parents continue to work. If you were always planning on being a dual income family before the diagnosis, you can usually continue on that course. You will just want to connect with a competent childcare provider. Typically, you do not need a special childcare provider for a baby with Down syndrome—just someone who is welcoming, responsive, and good at commu-

nicating with you about your child's needs. You may also need to consult with your doctor before placing your child in a childcare setting before heart surgery to avoid having to cancel or reschedule because of exposure to other childhood illnesses.

Family Stories

I have a thirteen-year-old son with Down syndrome and went back to work when he was about two months old. I used daycares in people's homes for the first several years. It worked out well for me. I was able to find daycare providers who were willing to have birth-to-three [service] providers come to their homes. I was also able to have some therapies in the evenings and had good communication with the providers that I didn't see very often. At this point, we have high school or college students come to our house, which he absolutely loves. It's working out well; but if I had it to do over again, it would be nice to have a good relationship with a daycare, where he could have continued going when he was older. Work and family is always a balancing act. But, I really can't say that the balance was any more difficult than with his older brothers. I am lucky to have plenty of vacation days to take care of any doctor's appointments; and he didn't have any real major health issues. I do understand the concern of having a child with special needs and trying to continue working, but it wasn't the issue I thought it might be. One friend of mine, a single mom with a fourteen-year-old daughter, has a great relationship with the local YMCA. The daughter is now a counselor in training for the summer day camps. They're building a great inclusive program because of this child. It's quite a success story. —Tamara

When Gabby was born, she was the youngest of four daughters who were close in age. I had always intended on returning to my career at some point, but I was thankful to be home in that first year when heart surgery and other medical concerns were pressing. When I finally returned to teaching law school classes, I was fortunately able to teach with a part-time, flexible arrangement. In Gabby's teen years, she has more medical issues than most teens with Down syndrome. As it turns out all three other daughters have complex medical needs, something we could never have anticipated. Having a rewarding job with flexibility has allowed me to meet the children's needs while meeting my professional goals. —Nancy

Family Life

Sometimes parents also worry about family life. Will we still be able to go on vacation? Will we still be able to play sports and games together?

For the most part, family life with a child with Down syndrome isn't much different than it is for other families. Most of us still go on vacation, play games together, go on adventures, and our child with Down syndrome is just part of the mix. They might need some extra help with certain activities or have some health limitations, but they usually follow the lead set by your family. So, if you have an active family that likes hiking and swimming, your child with Down syndrome will likely do those things as well. And if you have a musical family that likes to play instruments, your child with Down syndrome will probably pick up on those interests. Our recommendation is just to make plans, include your child with Down syndrome, and see what they can do.

Family Stories

We've had so much fun as a family—apple picking and going to high school football games in the Fall; tubing down rivers and hiking in the summer; cheering at lacrosse games in the spring; and going on vacations everywhere from DisneyWorld to Delicate Arch in Utah. Sometimes we might need to cut a hike short or play Uno instead of a more complicated card game to accommodate for Andy, but it really isn't much different than the accommodations we make for the other kids because they have something else going on. In the end, we still have a great time going on adventures together! —Stephanie

LOOKING TO THE FUTURE FOR YOUR CHILD

Understanding Education and Learning

In general, many young people with Down syndrome today are achieving more at school and in the workplace than ever before. Outcomes for people with Down syndrome vary. Educational expert, Frank Buckley, explains that almost all people with Down syndrome have mild to moderate intellectual disabilities that cause significant learning difficulties and some (perhaps 10-15%) experience more complex behavioral and cognitive challenges. Federal laws, such as the Individuals with Disabilities Education Act (IDEA), help students with Down

syndrome get the supports they need to learn the same types of material as their peers in public schools.

Changing social attitudes have reduced isolation, improved services, and offered more stimulating and richer opportunities to young people with Down syndrome. Over the past 40 years, cognitive and educational research has identified many of the specific difficulties experienced by children with the condition. This produces more effective early intervention and education, and helps young people with Down syndrome achieve better reading, speech, and math skills to participate more fully in schools and communities.

The outcomes for children with Down syndrome depend on a combination of their cognitive ability, their individual strengths and challenges, the opportunities a specific community provides, and the education and influence of their parents or caregivers.

The healthiest outlook may be to influence the factors you can control to foster an atmosphere where your child has the best chance to thrive. Accept your child regardless of his or her potential “outcome,” and enjoy your child for their specific and unique personality.

Finding Educational Tools and Programs

Many books, products, and resources can help a baby with Down syndrome start learning right away, including the following:

- [*See and Learn Kits*](#)
Materials aimed at teaching young children with Down syndrome speech, reading, and cognition skills, including learning apps.
- [*Beyond Play website*](#)
A catalog of educational toys. These resources can also provide great gift ideas for family and friends.
- [*Activities for Babies with Down Syndrome*](#)
Videos of activities to promote learning and growth for babies with Down syndrome.
- [*Down Syndrome Education International \(DSEI\)*](#) and its partner [*Down Syndrome Education USA \(DSEUSA\)*](#)
These organizations offer evidence-based resources and services to support families and educators. Each organization also offers learning, communica-

tion, and education resources. See their websites for further information and contact details.

- **Gigi's Playhouse**

Gigi's Playhouse consists of a large network of Down Syndrome Achievement Centers that offer therapeutic, educational and career training programs at locations across the US.

Enjoying Recreation

Sometimes new parents worry that their child will be unable to do some of the activities and events they once imagined. While this may be partly true, people with Down syndrome enjoy many different recreational activities, ranging from basketball and martial arts to ballet and photography. Much like typically developing children, each individual has their own strengths and interests. People with Down syndrome have earned their black belts in Tae Kwon Do, have become Eagle Scouts in Boy Scouts, golf competitively, and more. As your child grows and develops different skills and interests, you will both discover what recreational activities are most rewarding and fun for your child. These recreational opportunities are also great ways for making friends who have similar hobbies.

As you and your child look for recreational opportunities in the coming years, consider the following:

- Local neighborhood dance classes, sports teams, scout troops, art or photography classes, and martial arts classes. It is increasingly common to see children with Down syndrome as part of the activities and teams in any local area. However, each child's success usually depends on whether an instructor is patient and willing to make some accommodations when needed.
- City or county recreation departments that have a full range of camps, activities, and sports teams for children. These recreation departments may have teams and classes that include everyone and also activities specifically adapted for people with disabilities.
- School teams and activities ranging from the yearbook club to the swim team, just like all children who attend the school.
- Inclusive recreation opportunities that actively seek out people with disabilities to be included with their peers, such as Unified Sports (through Special Olympics) which unites people with and without disabilities on the same team.

-
- Activities and events specifically for people with disabilities, such as Challenger League Baseball and Special Olympics.

Over the years, many opportunities will arise for your child to try out different activities and settings to see what works best. Parents often find it helpful to avoid setting limits on their children and then try and see what they can achieve. You can think of these different types of activities as a buffet, and you can fill your plate with an assortment of activities that match your child's interests and needs. Parents and instructors may need to be creative in making accommodations or flexible in finding sports teams with the most appropriate competitive level. Ultimately, most children find activities and hobbies with which they can flourish and have fun.

Family Stories

Scarlett loves gymnastics. She started gymnastics at 22 months old. She will stop and do forward rolls often. She loves to color and ride her bike. But her favorite activity is playing with her family and friends. —Laura

My daughter loves music and dancing especially when performing for others. She loves when people are clapping and happy because of what she is doing. —Danielle

Going to College

Sometimes new parents also wonder if their child with Down syndrome will have the opportunity to go to college. Approximately 250 college programs nationwide invite students with intellectual disabilities to pursue post-secondary education—schools like Vanderbilt, Clemson, and Colorado State University. Each program is different, but most are typically certification programs that offer some life skills courses, electives, and independent-living options.

See ThinkCollege.net for more information.

Family Stories

*When my daughter was born, no one was talking about people with Down syndrome going to college. But 19 years later, she had college options. Now, she is a college girl living her dreams. She has the same hopes, dreams and challenges as other college students. Have high expectations and dream big. Never let your own fear stop your child with Down syndrome from living his or her dreams."
—Jawanda, Rachel's Mom*

Love and encourage your baby and they can live their dreams. I am living my dream of being a college girl. I go to college just like my friends. I have Down syndrome, but I am not Down syndrome. I am Rachel, and I love my life.” — Rachel

Making Financial Plans

New parents often wonder how to start planning their child’s financial future. First, be sure to gather your bearings and figure out the supports already available to you between social security and other resources. Then, you can consult with an attorney or financial planner experienced in special needs trusts to help you explore your options, including special needs trusts, irrevocable trusts, and ABLE accounts available in some states. One key to remember is to avoid saving any money in your child’s name before consulting with an expert; otherwise, your child could lose some support services. You have plenty of time to figure out the best financial plans for your child.

For more information, see [The ABLE National Resource Center](#). You can also visit [DownSyndromePregnancy.org](#) for the article, *“Financial Planning and Special Needs Trusts.”*

Finding Employment and Living Independently

Another question new parents usually ask about the future is whether their children will be able to find a job and live independently. Certainly, there is no way to make any predictions just after your child is born, but people with Down syndrome can find many different kinds of employment based on their skills and interests. There are people with the condition who are actors, photographers, nursing and teaching assistants, restaurant/business owners, custodians, employees at grocery stores, and assistants at libraries and law offices. While the unemployment rate for people with intellectual disabilities is currently challenging, the opportunities continue to improve with rising generations of children who are included in their schools and communities. Employment typically also involves some degree of support and job training, and support services offer help along the way.

One concern for new parents may also be whether their new baby will live with them indefinitely. Soon enough, those new parents start to worry that their child will *not* live with them forever. The situations are very different depending on your child and family’s preferences and needs. To address those different cir-

cumstances, there are also a variety of living arrangements available for people with Down syndrome, including living at home, living in a group home with residential support, or living with roommates, a partner, or alone and receiving some level of support services.

See [Charting the Lifecourse](#) by the UKMC Institute for Human Development.

Family Stories

Throughout school, my son was included with his peers at school, he was given chores like his sibling, and we expected he would get a job someday. When he was 16, Andy told us he wanted to get a job with his friends at the local grocery store in our neighborhood. My mind started churning about how we could get him a job coach and talk to a service agency, but Andy meant that he was telling us what he was going to be doing that day. While I was cooking dinner, he took off in his bike and went to the front desk to ask how to get a job there! I had no idea he was doing that until he called me from the store. They were so impressed with his initiative that they said they would be happy to hire him if he went through the application and interview process. He's now worked there for over 3 years.

When he was about 8, he also started showing a real eye for photography, so we cultivated that talent over the years as he participated in school contests, classes, and exhibitions, and now he's starting to build a career as a professional photographer.

He still struggles with reading and math, and even though we've worked really hard on those things, we've also discovered that there are things more important than academics... like ambition, drive, confidence, work ethic, and the discovery and cultivation of talents. My biggest recommendation for parents of younger kids is to give them chores early on to learn work ethic and help them discover and build their talents.—Stephanie

Falling in Love

Sometimes new parents also wonder if their child will fall in love and find a spouse. People with Down syndrome develop at about the same rate as everyone else in terms of maturation and their desire for love and intimacy. So, people with Down syndrome usually have boyfriends and girlfriends, and some get married, though they usually need extra support.

For more information, see ***Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality*** by Terri Couwenhoven, M.S., but you might want to wait a while on that!

Related Articles on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for articles such as, *“Working Moms,” “Single Ladies,” “Support for Dads,” “Learning to Teach Baby,”* and *“Slice of Life.”*



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LIFE GLIMPSES

The stories below offer a glimpse into what life is like for families at different stages, ranging from toddlers to adults. Each family shares that common link of Down syndrome, but their lives are very different as they deal with adopting a child; single parenting; adjusting to different health issues, cultures, and sibling dynamics; and exploring the interests, challenges, and strengths of each individual child.

Alexander

From Alexander's mom, Patti:

Alexander was placed in my arms at five weeks old when he completed our family of five. I was scared. I had never been around any children with Down syndrome. I knew absolutely nothing about it, but I knew that I was in love with my son and that God would guide us on our new adventure. Alexander has had his share of medical issues, and he keeps a smile on his face through all of it. No matter what, he is a fighter. He was a happy baby, and despite his medical issues, he reached his milestones about on target, and he can sign 66 signs.

The biggest change to our family has been the new outlook on what's important and what's not, which battles to fight, and which ones to walk away from. My teens

are forever changed by their brother. Alexander wants his brother to style his hair; he wants his sister when he gets a boo boo; but don't dare let mommy or daddy get out of his sight. My son is four now, and he gets out of bed every morning ready to get on the pre-school bus and work hard. Then when he gets home, he takes a long nap.

He loves to go to church, rearrange cabinets, play outside, ride in police cars, and, yes, go to the doctor and therapy. No matter what he does, he works hard and puts his heart into it. My two older children want to have jobs helping research Down syndrome or nursing—all because of their brother. Alexander is your typical loving, stubborn four-year-old who loves hiding the remote from daddy and having his sister paint his toenails while he scribbles on my walls—and I want him no other way! There are no typical days at my house. Every day is a loving learning experience from Sweet Alexander, my son with the “extra sugar.”

Brynnlie Grace

From Brynnlie Grace's mom, Tisha:

Brynnlie Grace is four, the youngest of our three children and our only girl. There were complications throughout my pregnancy with her, and we discovered at birth that she did indeed have Down syndrome. I remember gazing at her small, folded ear, at the crease across her tiny hand, at the sweet gap between her toes and wondering (with some fear and anxiety) what the future would hold.

I could not have imagined how much fun life with our little princess could be! Brynnlie is a joy to all of our family and friends. Her big brothers adore her (except maybe when she is knocking down their Lego creations). She is sweetness and smiles, with plenty of sass mixed in. Right now her favorite word is “no,” whether she means it or not. She loves to be independent, and frequently pushes a chair across the kitchen to get to her beloved snack cabinet. She loves to play with her babies, pretending to be mommy—leaving the house with her baby doll, purse, keys, and phone!

Brynnlie goes to the early childhood preschool program in our school district four mornings a week. She is primarily in a special education classroom where she receives extra help along with speech, occupational, and physical therapy. She currently spends at least 25% of her time at school in a typical class, with a goal to increase that percentage. She loves her teachers and friends at school. Her vocabulary is growing every day, and she knows colors, numbers, and some letters too.

The only health issues we have had to deal with have been similar to those many typically developing kids encounter. She has mild asthma, and she had her tonsils removed this past fall due to moderately severe sleep apnea. None of those concerns seem to slow her down much though. She is always ready for a wrestling match with her big brothers or a good game of chase with the family dog or cat. She is just about to start ballet class for the first time, and we are all so excited to watch her twirl.

I still don't really know what the future holds for Brynnlie, but I am feeling much less anxious. We are all so grateful just to have this little girl in our world.

Kaia

From Kaia's mom, Hikaru:

We are a family of five, with three school-aged children: Eirik in fifth grade, Soren in third grade, and Kaia in kindergarten. Our schedule is crazy, like many other families with three school-aged children, running from one after-school activity to another. During breaks, we love to travel together, camp when the weather is nice, and ski one or two times a year. Kaia has Down syndrome. Her extra chromosome hasn't honestly affected the things we do. We ask our boys if they feel their activities are in some way affected—their answers have been no.

When we found out about her Trisomy 21, we were comforted by the amount of information and shared experience accessible to us. Then, she was diagnosed with infantile spasms at 9 months. There was very little information, and it was a lot scarier. She fortunately responded well to the treatment and has been hypsarrhythmia-free since 11-months-old. While it's hard to know if it is consequential or not, she's going about life at a much more leisurely pace than many of her peers with Down syndrome.

I must admit, whenever her birthday or IEP meeting approaches, I get pangs of pain and panic—she's not yet doing this, she's still doing this. Kaia has to really work at picking up tasks that come so easily for other kids, and it's so not fair. But these pangs are quite short-lived. She smiles, gives me the greatest hug ever, and everything is alright.

Raising Kaia has made me consciously embrace every person in his/her entirety. Her presence has clarified that all three of our children have very distinct needs. I know I'm a better advocate for all of our children and for others that I care about, because of Kaia. I'm continuing to learn to notice and appreciate things that are truly pre-

cious in our lives. I never knew I could love this deeply.

Diego

From Diego's mom, Brenda:

Diego came into our lives more than eight years ago. It was wonderful because we got a new member of the family. Even though we did not know him, we had an unconditional love for him. My son was already diagnosed with Down syndrome. We were scared, but we were prepared to help him, along with our loving team of doctors, nurses, therapists, interpreters, and social workers.

Look at us now! A day with Diego never has a dull moment. "Wake up time to get ready," I say to Daniela and Diego at 7am on a typical school day. Daniela is my 12-year-old daughter. Diego usually needs some persuasion to wake up because he is not a morning person. After he wakes up, I help him get ready for school; he gets dressed with some assistance from me sometimes. Next, Diego always tells me what he wants for breakfast—usually French toast, scrambled eggs or chorizo, and orange juice. While Diego eats breakfast, he is interested to know what he will eat for lunch at school, so he checks the lunch menu. When it is time for Daniela to head off for school, Diego likes to say good-bye. Then, Diego continues waiting for his bus and finishes up his breakfast. Sometimes he plays with his toys for a little bit until his bus comes. It is funny because at night he usually complains about going to school, but when the bus comes, he is excited to head off to school. Before Diego gets on the bus, he never forgets to say bye to our dog, Candelas, and tell him to be a good boy.

When Diego returns from school, I usually check his backpack. He has a folder where his teacher reports Diego's behavior and what he did that day, such as art, music, PE, speech. I am glad that he usually comes home with happy faces. When he gets a sad face, we usually talk about it and see what is going on. When he behaves well in class, he can get prizes from me or his teacher. If Diego does not behave well, I take away from his iPad or computer time. After school, Diego plays with his iPad or enjoys free time. Afterwards, I ask Daniela and Diego to set the table and get ready for dinner. Diego gets happy when Papi gets home. He always greets Papi with a big smile and a hug. Everybody helps to clean up, and Diego does his homework with help from Daniela, Papi, or me. Then he gets a little more free time, and we get ready for the next day. Diego enjoys choosing his clothes. Depending on the season, we usually have after-school activities like baseball, English class, and biking. You can see our routine is chaotic but always full and fun. Our everyday success comes from a routine, and it helps our whole family, especially Diego. We feel

blessed to have our family just like it is.

From Diego's sister, Daniela (12):

I was four when Diego came into our family. When my parents told me he was going to have Down syndrome, I did not feel any different toward him. I knew I would love him and that we would have fun together. I still feel the same way. We have fun together even though we argue and drive each other crazy all the time. I am proud to be his sister. There is never a dull moment with Diego!

Cristian

From Cristian's mom, Yadira:

Cristian was born nine years ago on one of the happiest day of our lives. He was born healthy and beautiful. After we went home, we noticed that he wasn't gaining weight. So, the nurse visited us constantly. We took him to the clinic about three times those first weeks of his life. The doctor told us that he might have Down syndrome or murmurs! Our surprise was that he had both. We found out about this more than a month after he was born.

Having a child with Down syndrome is not always easy, but who said being a parent was easy? No one has a guide; everyone learns from experiences.

Cristian taught us about strength at two months of age after he had surgery. He was very delicate. He stayed in the hospital more than a month. After that, he had a few more visits to the hospital—not for his heart but for other health issues like asthma and pneumonia. Cristian now takes medication for thyroid, reflux, ADHD, and sometimes asthma. Everything is under control. He hasn't visited the doctor for emergency problems for about three years, not even for a fever. He has been staying really healthy.

Cristian is sweet, strong, and fun, but he is also short-tempered and impulsive! All this makes him the kid that I love—the kid that changes my mood when I feel sad or mad. He makes me laugh when I think I can't laugh. He gives me strength and faith that everything is possible.

Cristian loves playing baseball with his big brother, but what he likes the most is technology. He has an ability with iPads, iPods, and cameras. He loves taking pictures just like mommy, and loves to sing like daddy. Cristian loves music and loves to get attention from everyone.

Cristian has been in therapy since he was four months old with a program called Infant Toddlers. After he was three, he started school and has been receiving therapy there. They work with him one on one, and I've seen great progress. He signs, says many words in Spanish and English! I think that makes it a little harder for him, but he is learning to communicate very well. He seems really happy, and this makes me happy too.

Cristian has taught us that life is full of goals, goals that you can reach if you really work hard for them. I'm proud to say that I'm his mom and to see that he also has a great dad and brother that love him as much as Cristian loves us.

Caleb

From Caleb's mom, Marleen:

Caleb, my precocious 10-year-old son, has Down syndrome, and I accept and love him for who he is. Through early intervention, he can read, write, ride his bike, and communicate his basic needs. Like most fourth graders, he loves using electronics, online shopping, playing various sports, eating mac and cheese, being outdoors, and playing with friends. He also loves all animals. I still recall the day Caleb brought me a frog. He had a huge smile on his face and was so proud of his accomplishment. After dismissing my fears, I sat down and watched while he played with the frog.

Speaking to and interacting with Caleb is always an enjoyable and enriching experience. Like all 10-year-olds on the cusp of becoming a teenager, Caleb is inquisitive and adventurous. While getting used to crowds can be too much for him, running into the ocean to swim is almost natural for Caleb. His ability to be generous and kind is astonishing! While no one is perfect, Caleb has taught me to be patient and more accepting of others. I am constantly in awe of Caleb's perspective on life as depicted in this conversation.

Caleb: "Mommy, I'm in love!"

Me: "What?"

Caleb: "I'm in love with two girls." (Caleb looks back, and I notice two little girls standing in the aisle with their parents.) "Mommy, I'm crushing!"

Me: "You mean you have a crush."

Caleb: "Yes, I have a crush on two girls."

Me: "Caleb, you need to pace yourself; you can only love one girl at a time. Two girls mean trouble."

Caleb: "Girls are trouble. I love girls!"

Having Down syndrome is not terminal; it is simply a medical diagnosis. It does not define who you are. The more we know about this condition, the more prepared we are to deal with the challenges associated with it. As a mother, I know firsthand the challenges faced by our Down syndrome population. Believing in the old adage that "knowledge is power," I made it my mission to find information that will enable me to be the best advocate for Caleb. His success and ability to become a functioning member of society depends on support from me.

Life is short and precious! Every morning, we are given the opportunity to start new; we cannot change what happened yesterday, or predict what will happen tomorrow. We can, however, embrace the present, love and accept our children, and enjoy them for this season.

Abigail

From Abigail's mom, Rachelle:

Abigail is 12 years old and is the youngest of our three children. After she was born, we found out that she had a hole in her heart, and it was an AVV canal that would require surgery. The first year or two were busy with therapies and doctor visits. I felt like we were going to spend her entire life going to the different clinics at our local children's hospital. She ended up having her AVV canal repaired, got pneumonia, had a tonsillectomy/adenoidectomy, tubes in her ears, and a correction of a duodenal stenosis.

Abigail now only goes to the doctor for regular check-ups and illnesses. It seemed like we would never get to this point.

Being the youngest sibling, Abigail is the family comedian. She knows just what

to do to irritate her brother and sister; she also knows how to make us all laugh. Sometimes Abi says things and we aren't sure if we don't understand her or hear her correctly. For example, when she was around 6 years old she shouted, "Oh, Archimedes!" We all looked at each other wondering what she had said. After having her repeat it a few times, we put our heads together and realized she was quoting a movie. It became a favorite phrase for her, always catching people off guard!

Abigail uses her sense of humor and love of socializing to make every trip to the store an adventure. I must admit that most days I would love to race through my grocery shopping and get on with my day. Abi sees the outings as a chance to meet people and experience life in a way most of us do not. She will talk to everyone that she can! She will introduce herself, occasionally forcing me to shake hands with these strangers as well. She compliments ladies on their nails, shoes, etc. She offers hugs to the people that she can sense need them. She asks to look at babies in carriers. For Abigail, shopping is the event, not something to be rushed through. By the time we leave the store, the people that Abi has met throughout the trip are now waving and saying, "Goodbye Abi!" She brightens their days.

Melanie

From Melanie's mom, Suchong:

When Melanie was born with Down syndrome 15 years ago, we were shocked and did not know what to expect. She had to stay in the intensive care unit for a month with medical issues. Now she is a very bright girl with lots of energy as a teen.

Melanie does lots of activities outside of school: swim team, Taekwondo with a first degree black belt, dance class, piano, voice lessons, and drums. Also, she goes cycling with her dad and roller skating. She has been on the local swim team for three years and knows all four stroke techniques. She will be in high school this year and wants to be on the high school swim team. Melanie is also involved in the Special Olympics swim competitions, and she volunteers for the Taekwondo special needs class every Saturday. She participated in the Taekwondo "Demo Team" a few years and went to lots of tournaments and learned to use weapons.

At school, Melanie works hard and is very independent. She is a great reader, but she struggles with math and comprehension and needs extra tutoring and special education services at school to help her succeed. We also work to make sure she knows how to be independent, such as teaching her to cook, clean, take medication, use social media, and text her friends. Melanie has had her iPhone for a few years, and

it helps her check on her daily schedule and download music. Melanie loves to stay home alone when she does not have school so she can sleep in until 11 am like a typical teenager.

Melanie has many friends that spend time together going to movies, shopping, going to concerts, and sometimes stopping by Starbucks on the way home. Melanie has many goals for herself too, including graduating from high school, attending college, working at a job that she will enjoy, learning how to drive a car, and living independently.

Our dream is that someday she can be a Taekwondo master and swim instructor, but that will also depend on what Melanie wants at the time. We're constantly impressed by the young lady she's becoming, who she wants to be, and what she has accomplished already.

Caroline

From Caroline's mom, Shelly:

Caroline's life is full and robust, and it has been from the beginning. She has been active in dance, horseback riding, mainstream school classes, Girl Scouts, National Charity League, church youth group, handbells, choir, cheerleading, volleyball, bowling, soccer, basketball, and tennis. She was a Varsity cheerleader and worked at a bakery during high school. She has held a paid job as the seating hostess at a local restaurant for the past three years. She is currently taking college courses at the local community college and is also involved in a job internship program where each semester she works at various locations, including the grocery store, children's hospital, health club, and retirement center.

Her goal after finishing community college is to complete a Certified Nursing Assistant program so she can get a job in a hospital or assisted living facility. Caroline is also already making plans to move to her own apartment when she is 23 (she is currently 19). We personally know four college graduates with Down syndrome, and they are working and living independently. Our goals for Caroline are the same as our goals for our other children—leave our house and have a fulfilling life!

It has not always been easy, and there are many times I have had to advocate for Caroline to have these opportunities. However, now she is learning to advocate for herself and her own dreams for her future. She will need supports her whole life. But she will have her own life.

Related Articles on DownSyndromePregnancy.org

You can visit DownSyndromePregnancy.org for articles such as, *“Learning to Teach Baby”* and *“Slice of Life.”*



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GETTING MORE SUPPORT

You may find it helpful to reach out to professionals, local Down syndrome organizations, online communities, or other parents to assist you. Many parents may turn to online resources or communities right away but may wait to meet in person until a later stage. Other parents may crave an in-person connection with experienced parents right away. Still others may benefit from support but are uncertain of the landscape or where to turn.

Consider your options for support, and consider your own comfort levels. As you do, please understand that all parents have been through the adjustment to a diagnosis. They truly understand the emotional journey of a parent who has received a new diagnosis. While they may be all smiles today, most will openly share with you stories of any difficult times post-diagnosis and understand your current feelings.

FINDING GENETIC COUNSELORS AND GENETICISTS

A genetic counselor or geneticist is trained to offer you a more comprehensive explanation of Down syndrome after your baby receives a diagnosis. Even though your health care provider likely has a basic medical understanding of the condition, a knowledgeable genetic counselor can provide a broader view about life with Down syndrome, including detailed information about services,

modern advances, local resources, and potential outcomes. You can perform your own search at the [National Society of Genetic Counselors](#) or the [American College of Medical Genetics](#).

FINDING A DOWN SYNDROME CLINIC

Sometimes a regional area will have a Trisomy 21/Down syndrome clinic. New parents usually schedule an appointment with one of the specialists at the clinic and see them regularly. Generally, clinics do not provide the daily care that a pediatrician does. Instead, the clinic may serve as a “check point” to present your child’s medical history and developmental progress. From this information and a physical exam, as well as an evaluation, the clinic specialist may be able to recommend additional therapies or tests to make sure that your child is receiving everything needed. These clinics are staffed by physicians who are experts on Down syndrome and have seen many children with the condition. Unlike a pediatrician who might have one or two patients with Down syndrome in their practice, these specialists see many children and know how to identify subtle medical issues.

Clinics vary in the services they provide, but at some clinics, you may be able to see specialists or therapists on the day of your visit. The clinic may also be able to help you with contacting a local support group. The National Down Syndrome Society (NDSS) provides a [list of clinics](#) separated by region and state.

You will also want to check with your health insurance about coverage for clinic services because some providers require a copay for each specialist. You’ll want to make sure you are not surprised by the billing procedure for a clinic visit.

You can also access the online, fee-based tool, ***Down Syndrome Clinic To You (DSC2U)***, which was created by Dr. Brian Skotko, MD, MPP, and the clinical and research teams from the Down Syndrome Program and Lab of Computer Science at Massachusetts General Hospital. DSC2U asks you to answer health and life questions about your loved one with Down syndrome, and the responses are “analyzed by a computer, based on state-of-the-art guidelines designed by national Down syndrome experts. The caregiver will instantly receive two personalized documents: one for themselves and one to share with their primary healthcare provider. These documents contain customized suggestions that are designed to help their loved one get healthcare tailored to their own specific needs. The documents are based on the caregiver’s answers to the DSC2U

survey and draw on national guidelines for the care of persons with Down syndrome."²⁸

FINDING YOUR LOCAL DOWN SYNDROME ORGANIZATION

Your health care provider may give you contact information for your local Down syndrome organization. If not, an internet search should reveal any groups in your area. Most groups have a website with contact information.

Most groups also have a new parent outreach coordinator or similar person, and websites usually provide their email addresses or phone numbers. You can also ask if the group has a new parent support program, and if a parent is available for one-on-one support. If you prefer to speak to someone who has faced issues similar to those diagnosed in your baby (a specific heart defect, for example), please ask the contact for a referral.

Contacting your local group and speaking with a member will also give you an opportunity to learn about the local Early Intervention services, medical facilities, the educational system, social support, recommended medical providers, and your state's laws and procedures for assistance such as SSI or Medicaid.

In addition to one-on-one support, you may wish to attend a support group's meeting, playgroup, or social event to meet other parents. The programs offered by local groups can vary widely depending on where you live. Some have paid staff and robust programs for all ages while others are run by a small group of dedicated volunteers; however, almost all of them make new parent support a priority.

To find a group in your area, you can check the resources below:

- [*NDSS Affiliate Locator*](#)
- [*Global Down Syndrome Foundation Organization Locator*](#)

28 <https://www.dsc2u.org>

REACHING OUT TO LOCAL PARENTS

You may find it helpful to reach out to local parents on your own. Whether a friend of a friend has a loved one with Down syndrome, a member of your religious or civic organization has a loved one, or you remember a friend from your past who has a relative with the condition, most people in this community are more than happy to speak with a new parent. You may wish to ask your doctor or genetic counselor for the name of any other patients who have a child with Down syndrome. Another idea is to contact the special education department in your local school, or contact the local EI program to see if they have a way to connect you with other parents.

Many new parents have a heightened awareness after diagnosis, seeing people with Down syndrome in numbers they never noticed before. Often, parents wish to approach these strangers, but are uncertain if it is appropriate or unsure of how to do so.

A good technique is to approach and ask, “Do we have something in common?” Usually a parent will then look up and realize the connection, and a friendship may blossom.

FINDING ONLINE SUPPORT

A variety of internet support groups and blogs offer new parents support, answers to questions, and hope for the future. The advantage of internet support is that a parent can ask a question or make an introduction any time of the day or night, and await responses from those who are further along on their journey. In addition, online support can provide the opportunity to find people who are experiencing a new diagnosis at the same time. You’re also more likely to find a more diverse collection of parents or caregivers who can relate to your family situation, ethnic background, or specific medical issue. You can also view pictures of other children and read stories of challenges, successes, and everyday life. Further, new parents who are feeling emotionally volatile do not need to worry about their ability to “keep it together” when communicating.

The drawbacks of internet support are security concerns connected to dissemination of information, geographic distances from those giving support, possible lack of knowledge about local information, and the occasional fake participant.

Parents should use the internet as a valuable tool but exercise caution and good sense. The more well-known and/or useful internet support groups include the following:

Discussion Groups

- *Down Syndrome Baby Center Forum*
Volunteers moderate a discussion board that offers daily support to parents of children with Down syndrome.
- *Down Syndrome Diagnosis Network (DSDN) Facebook Groups*
This network offers Facebook peer-to-peer support organized into birth club years, as well as groups focused on specific health issues and cultural identities.

A Word About Language

Once you become involved in the community, you may notice that the parents of children with Down syndrome use specific language to refer to their children. One common idea is called “People First” language. For parents, that means referring to their child with Down syndrome by saying “my child with Down syndrome” rather than “my Down syndrome child.” The reason behind this is that the language shows that the most important thing about a person is not a diagnosis but the individuality as a person. However, some adults with disabilities are increasingly advocating for wording such as “disabled person” or “autistic person” to show pride in being a member of the disability community. It is always important to respect the language a person uses when they refer to themselves.

Typically, people in the United States use the term, “Down syndrome,” while people in the UK use the term, “Down’s syndrome.” Also, while professionals occasionally use the term “mental retardation,” many parents and advocates bristle at this description because of the baggage that comes with the words. Some other descriptions you might hear are intellectual disability or developmental disability, which are currently the more preferred terms.

Family Stories

Our local group and online groups have been life changing. Connecting with families took the isolation out of our diagnosis. Families were willing to share their comforting stories. They also were willing to give guidance on therapy, and how to talk to others. I love to follow other families on Instagram. Follow hashtags to find them.—Laura

Meeting, visiting with, and becoming life-long friends with other parents has been the best. —Pat

Both the local playgroup I attend and the online group have helped! Every single child is different, Down syndrome or not, and I remind myself daily that all children develop at different ages. —Amanda

DSDN (Down Syndrome Diagnosis Network) has been an amazing resource! It's so nice to be able to have mamas that understand and get what you're going through because they're going through a similar journey in regard to raising a child with Down syndrome. Also, Gigi's Playhouse of Atlanta & Down Syndrome Association of Atlanta have been wonderful resources, and I have met many good friends through these organizations and their events. —Ashley

Related Articles on DownSyndromePregnancy.org

Visit DownSyndromePregnancy.org for articles such as, "[Dealing with Comments \(Includes Sample Letter\)](#)" and "[15 Reasons to Reach Out to Your Local Group.](#)"



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FINDING RESOURCES

When a family learns their child has Down syndrome, they often experience anxiety about the future. Finding out more information about Down syndrome largely comforts parents but can also lead to more worries.

On one hand, parents may have outdated ideas about Down syndrome based on limited exposure and knowledge. If new parents research the condition, they hopefully will learn about the advances in medical care, increasing social acceptance, leaps in the educational field, studies reflecting healthy family impact, and the current status of promising research on cognition.

However, new parents also will likely encounter a list of issues that are “associated” with Down syndrome, along with quite a bit of outdated or incorrect information as well. These discoveries may increase a family’s anxiety.

Our book gives a general overview on potential issues, with a focus on the newborn period, but we also provide resources so you may obtain more information from reliable sources when you are ready.

NATIONAL DOWN SYNDROME SUPPORT ORGANIZATIONS

The national groups which provide information and support to parents include the following:

- *National Down Syndrome Society (NDSS)*
- *National Down Syndrome Congress (NDSC)*
- *Down Syndrome Diagnosis Network (DSDN)*
- *Down Syndrome Education USA (DSEUSA)*
- *International Mosaic Down Syndrome Association (IMDSA)*
- *National Down Syndrome Adoption Network (NDSAN)*

IMDSA is an international group for people with mosaic Down syndrome, and the NDSAN provides a network for families considering adoption. NDSAN also maintains a registry of parents interested in adopting children with Down syndrome and offers resources about placing a child for adoption.

NDSC and DSDN also host annual conferences where you can meet with other families and attend breakout sessions focusing on different topics of interest.

NATIONAL DOWN SYNDROME RESEARCH ORGANIZATIONS

The following organizations engage in modern and very promising research into improving outcomes for people with Down syndrome and have very useful information about the status of current research:

- *LuMind IDSC Down Syndrome Foundation*
- *Down Syndrome Education USA*
- *Global Down Syndrome Foundation*
- *Jerome Lejeune Foundation USA*

The *DS-Connect* registry, sponsored by The National Institutes of Health (NIH), is a national resource where people with Down syndrome and their families can “connect with researchers and health care providers; express interest in participating in certain clinical studies on Down Syndrome, including studies of new medications and other treatments; and take confidential health-related surveys. These surveys are aimed at better understanding of the health of people with

Down Syndrome across their lifespans.”²⁹ If you are interested in participating, registration is free, and information is stored in a secure NIH database. Participation is completely voluntary, and you can request to be removed from the registry at any time. If you have any questions, contact the registry coordinators at DSCconnect@nih.gov.

NATIONAL DISABILITY ORGANIZATIONS

National disability organizations can provide additional information about caring for a child with Down syndrome. Some of the leading national disability organizations include the following:

- *American Association of People With Disabilities*
- *ARC*
- *Association of University Centers on Disability*
- *Special Olympics International*
- *Parent 2 Parent USA*
- *Family Voices*

NEW PARENT RESOURCES

Books

There are both practical guides and individual stories you can read. Pay attention to the date when the book was published, since research, social, and educational progress is constantly changing the landscape for people with Down syndrome. We understand the number of options can sometimes be overwhelming when looking online, so we've included a list of books that parents and leaders often recommend.

Parenting Books

- *Babies with Down Syndrome: A New Parent's Guide* by Susan J. Skallerup
This book provides a practical and comprehensive guide for infancy.
- *Down Syndrome Parenting 101* by Natalie Hale
This book provides organized advice, personal reflections, and explanations

²⁹<https://dsconnect.nih.gov>

to educate parents on a variety of topics, including handling behaviors, teaching reading, interacting with medical professionals, coping with the school system, and more.

- *The Parent's Guide to Down Syndrome: Advice, Information, Inspiration, and Support for Raising Your Child from Diagnosis through Adulthood* by Jennifer Jacob and Mardra Sikora
This book offers advice from diagnosis to adulthood with quotes from many parents.
- *What I Want You To Know: Messages Of Hope & Joy From Your Baby* by RA Hudson
This book, written by the parent of a child with Down syndrome, includes humorous and heartwarming notes to new and expectant parents.
- *Breastfeeding and Down Syndrome* by Ella Cullen
This book provides a detailed explanation about different strategies to breastfeed a baby with Down syndrome.

Compilations

- *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives* by Kathryn Lynard Soper
This is a compilation of stories about the journey from shock to the realization of what our children bring to our lives, including stories from mothers who received a prenatal diagnosis, including Nancy McCrea Iannone.
- *The Congratulations Project*
This is a collection of letters written by adults with Down syndrome to new members of the Down syndrome community. These letters are intended to inspire, encourage, welcome, and congratulate new parents and siblings of a child with Down syndrome.
- *Reasons to Smile: Celebrating People Living with Down Syndrome* by Andrea Knauss and Elizabeth Martins
Compilation of 56 short stories and photos by writers around the world celebrating the lives of people living with Down syndrome.
- *Common Threads: Celebrating Life With Down Syndrome* by Cynthia S. Kidder and Brian Skotko
This book features beautiful pictures and essays about life with Down syndrome.

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- *Gifts 2: How People with Down Syndrome Enrich the World* by Kathryn Lynard Soper
This is a compilation of essays from friends and family members about their experiences with their loved one with Down syndrome covering a range of different ages.
 - *Unexpected: Stories of a Down Syndrome Diagnosis* by Jennifer Jacob and Joelle Kelly
This books offers a range of candid diagnosis stories as told by families whose babies were diagnosed with Down syndrome prenatally or postnatally.

Memoirs

- *Bloom* by Kelle Hampton
Kelle Hampton, who contributed photography to this book, writes about how the grief following her daughter's diagnosis becomes eclipsed by embracing life and enjoying Nella's first year. Includes full color photography.
- *My Heart Can't Even Believe It: A Story of Science, Love, and Down Syndrome* by Amy Silverman
NPR contributor Amy Silverman writes about her daughter Sophie, but touches upon genetics, history, politics, pop culture, education, medicine, health care policy, marriage, motherhood, and family.
- *The Lucky Few: Finding God's Best in the Most Unlikely Places* by Heather Avis
This faith-based book shares insights from Heather Avis about her journey in adopting three children, including two who have a diagnosis of Down syndrome.
- *An Uncomplicated Life: A Father's Memoir of His Exceptional Daughter* by Paul Daugherty
Sports columnist Paul Daugherty writes about raising his mischievous daughter Jillian, from the uncertain time at birth through a lifetime of love and humor.
- *What I Should Have Said* by Rob Snow
Rob Snow, a comedian and father of a son with Down syndrome, shares a compilation of the funny responses he wishes he would have said in the moments when he's heard cringe worthy comments about Down syndrome.

-
- *Road Map to Holland: How I Found My Way Through My Son's First Two Years With Down Syndrome* by Jennifer Graf Groneberg

Jennifer Graf Gronenberg describes the first two years of adjusting to a diagnosis after learning that one of her twin boys was born with Down syndrome and her search to find balance and supportive relationships.

- *The Shape of the Eye* by George Estreich

This book, written by a poet whose daughter has Down syndrome, describes raising his child, including processing the diagnosis and dealing with the medical complications of a feeding tube, and also looks analytically at social attitudes towards disability, preconceived notions, and the concept of family.

- *A Good and Perfect Gift: Faith, Expectations, and a Little Girl Named Penny* by Amy Julia Becker

Amy Julia Becker shares the deepest thoughts from her personal journal to give an honest and self-reflective account of her reaction to her daughter's diagnosis. The book illustrates the self-awareness she develops as she evolves to embrace the individuality of her daughter with Down syndrome and reconciles the circumstances in her life with her Christian faith.

- *Raising Henry: A Memoir of Motherhood, Disability, and Discovery* by Rachel Adams

Rachel Adams, a professor at Columbia University living in Manhattan, talks about the birth of her son Henry with humor and candor and tackles more complicated discussions about prenatal testing, social prejudice, medical training, and more.

- *Count Us In: Growing Up with Down Syndrome* by Jason Kingsley and Mitchell Levitz

Two men with Down syndrome share their personal experiences growing up with the condition and thoughtfully discuss the different aspects of their lives, including friendship, school, and adulthood.

Podcasts

- *The Lucky Few Podcast* by Heather Avis, Mercedes Lara, and Micha Boyett

Three mothers discuss their experiences as the parents of children with Down syndrome featuring guest experts from the community. About 30 minutes to an hour each.

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- *Down Syndrome Center of Western Pennsylvania at Children's Hospital of Pittsburgh of UPMC by Dr. Vellody Kishore*

Dr. Vellody Kishore, who is also a brother of a person with Down syndrome, covers many topics about Down syndrome ranging from research to medical issues to life outcomes, featuring expert guests. About 20 minutes each.

- *Unexceptional Moms* with Ellen Stumbo and Erin Loraine

Two moms discuss the joys and challenges of raising children with disabilities. Ellen also shares her perspective as a Latina in the Down syndrome community.

- *If We Knew Then - Down Syndrome Podcast*

Stephen and Lori Saux, the parents of a child with Down syndrome, interview experts about supports, therapies, education and society related to Down syndrome.

- *Bethany Van Delft on the Moth*

A comedian who is mother of a child with Down syndrome shares her poignant and funny insights. She also thoughtfully and humorously reflects about her experiences as a fierce advocate with her diverse background as the daughter of a Marxist Dutch dad and B14lack Puerto Rican mom.

National Basket program

- *Jack's Baskets*

This non-profit organization provides complimentary baskets with books, brochures, gifts, and more to new and expectant parents nationwide. You can contact them to request a basket from anywhere in the country.

Films and Online Video Clips

- *The Journey Ahead*

This video clip by the Down Syndrome Association of Greater Cincinnati (DSAGC) is produced in a comprehensive, documentary style.

- *Dear Future Mom* by CoorDown

This short international video by CoorDown is a video from people with Down syndrome with a message to new moms about their lives and their relationships with their moms.

- [*50 mums 50 kids 1 extra chromosome*](#)

This adorable video features 50 moms and their children with Down syndrome singing and signing a song together.

- [*Nothing Down About It*](#)

Mom, Oakley Petersen, describes how she adjusted to her son's Down syndrome diagnosis and learned to appreciate him as an individual.

Booklets

- [*Your Loved One Is Having a Baby with Down Syndrome*](#)

This booklet is for friends and family members whose loved ones are expecting a baby with Down syndrome. It gives them an overview of the condition and how they can best support you and know what to say. While the book focuses on expectant parent support, the content also applies for new parents.

- [*What Parents Wish They'd Known: Reflections on Parenting a Child with Down Syndrome*](#) by Kathryn Lynard Soper

The book compiles quotes from parents about what they wish they had known when learning about a diagnosis.

- [*A Promising Future Together*](#) by NDSS

This booklet shares information about using Early Intervention, finding support, caring for your family, and understanding general information about NDSS.

- [*Expecting an Extraordinary Life: A New Parent's Guide to Down Syndrome*](#) by the Down Syndrome Association of Greater Cincinnati

The booklet covers some of the basics about Down syndrome while also including essays from families about their lives.

- [*Coping with Loss*](#)

This booklet from Down Syndrome Pregnancy is for women who have experienced a miscarriage or infant/child loss. This is specifically to help them find resources and support during what can be a very difficult time.



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CONCLUSION

The Down syndrome community has a long tradition of paving the road for those who are behind us in their journey. As you go forward on this path of unexpected adventures, we hope this book will be a travel guide that you will consult on a regular basis. Although no one can truly know what to expect until they actually experience the journey, we hope this book will serve as a comforter, checklist, encyclopedia, translator, organizer, and shortcut as you explore this new territory. As we end this book, we know that you are just beginning your journey. If you follow us on the Down Syndrome Pregnancy website, you will find more resources and an entire community of people waiting to help you.

ABOUT THE CREATORS

Author Nancy Iannone



Ann Marie “Nancy” McCrea Iannone graduated with a Bachelor of Arts in English from Rutgers College, Rutgers University in 1989. She received a Juris Doctorate in 1994 from Rutgers University School of Law in Camden, where she graduated with High Honors and Tax Honors with Distinction and served on the editorial board of Rutgers Law Journal. Nancy spent several years practicing law and teaching writing to law school students before retiring after the birth of her second child. Nancy is now a writer, a tutor, and a part-time lecturer at Rutgers University School of Law in Camden.

Nancy lives in New Jersey with her husband, Vincent, and their four daughters, Samantha, Maria, Elena, and Gabriella. In 2004, Nancy and her husband received the news that their unborn baby Gabriella had both Down syndrome and a heart defect that would require open-heart surgery.

“Receiving and adjusting to Gabby’s diagnosis was the single most difficult thing I’ve ever done,” Nancy shares. “There is a feeling of isolation, a self-consciousness not seen since adolescence, fear of the unknown health issues we may face, awkwardness when telling people ‘the news,’ dealing with comments

from people. Yet that difficult time is separate from this life, raising an endearing and vivacious child whose curiosity and humor enrich all of our lives.”

Nancy started hosting an internet support group for moms with a prenatal diagnosis in 2006, and over the years saw a pattern in the emotional issues, the fears, and the questions of prenataally diagnosed parents. In 2007, Nancy wrote an essay entitled “A Hopeful Future” in Kathryn Lynard Soper’s book *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives*. Nancy is also the past Prenatal Outreach Coordinator for her local group, Knowledge and Information about Individuals with Down Syndrome (KIIDS). In 2010, she joined forces with Stephanie Meredith to create the first edition of “Diagnosis to Delivery: A Pregnant Mother’s Guide to Down Syndrome.” In 2012, she co-authored the booklet, “Your Loved One is Having a Baby with Down Syndrome,” and in 2015, she co-authored “Welcoming a Newborn with Down Syndrome” and the booklet, “Coping with Loss.”

Author Stephanie Hall Meredith



Stephanie Hall Meredith graduated from Brigham Young University with a Bachelor of Arts in English in 1997, a Master of Arts in English in 1999, and is currently pursuing a Doctorate in Public Health at Georgia State University. She has worked as a technical writer and a science/medical writer and currently works as the Medical Outreach Director at the University of Kentucky’s Human Development Institute.

Stephanie lives in Canton, Georgia with her husband, Justin, and their three children, Andy, Kate, and Lily Jane. Stephanie's first child, Andy, was born with Down syndrome in January 2000.

"When my husband and I found out that our son Andy was born with Down syndrome, we were 23-year-olds who were scared about the future ahead of us," Stephanie shares. "At the time, we felt overwhelmed by the news, and I was very depressed that Andy had to stay at the hospital to resolve some medical issues."

"The first time we started to glimpse 'normal' again was when a mom who provided support at the hospital showed us a photo of her son with Down syndrome on a bike. At that moment, my husband and I both thought that if the little boy in that photo was our future, then we could handle it."

"Now, that news has become an ordinary reality. Andy works as a photographer, grocery store front desk clerk, and coaches lacrosse, and his life is so full and meaningful. I am so fortunate to work in a field dedicated to advocating for people with disabilities, and I'm so grateful that Down syndrome has given us a clarity that has forever changed the way we see the world and the people in it."

Stephanie is the author of the nationally recognized booklets, "Delivering a Down Syndrome Diagnosis," "Understanding a Down Syndrome Diagnosis," and "Understanding Prenatal Screening and Testing for Chromosome Conditions," and the co-author of "Your Loved One Is Having a Baby with Down Syndrome," "Welcoming a Newborn with Down Syndrome," and "Coping with Loss." She also runs the National Center for Prenatal and Postnatal Resources where she hosts training for medical providers and advocacy groups on how to build relationships and improve the diagnosis experience for families. She works on federal-funded projects to improve employment outcomes for people with disabilities and is a public speaker on subjects ranging from serious topics like engaging in medical outreach to lighter topics about being the mediocre mom of a child with Down syndrome.

Contact Stephanie at stephanie.meredith@uky.edu.



Conny Wenk started capturing the beauty and personality of children with Down syndrome after her own child, Juliana, was born in 2001. Conny's blog and books blend gorgeous photography and personal essays from parents to give the audience an intimate glimpse into the lives of families who have children with Down syndrome.

"Photography has always been my great passion. But thanks to my wonderful daughter, my passion became my profession. When Juliana was born and diagnosed with Down syndrome, our world seemed to fall apart. After I recovered from the initial shock, I began to see with new eyes. I became aware that real beauty is much more than meets the eye, and how symmetric the face and body are. It's the inner beauty. Somebody with a beautiful mind and soul is a very beautiful person. And a happy one!"

Conny Wenk has published seven books:

- *Aussergewoehnlich* (2004 and a new version 2013): about 15 mothers and their children with Down syndrome.
- *Schmetterlingszauber: a celebration of the wonderful friendship of three little girls.*
- *Aussergewoehnlich: Väterglück: 22 fathers and their kids with Down syndrome.*
- *Freundschaft (Friendship): about young adults with Down syndrome and the bond between friends.*

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- *Aussergewoehnlich: Geschwisterliebe: 17 people with Down syndrome and their siblings*
 - *#46pluskocht: A cookbook with celebrity and star chefs and their sous chefs with Down syndrome.*

Since 2010 Conny has annually published her wall calendar, "A little extra," featuring people with Down syndrome, and you can also view her photography on Instagram at @connywenk.

For more information and to see her photography, visit Conny's websites:

- www.alittleextrabyconnywenk.com
- www.connywenk.com

Photographer Kelle Hampton



Kelle Hampton is a professional photographer whose goal is to capture beauty in its purest form, telling the story of those she photographs, with all of their quirks, their humor, and the spark of their personalities. Kelle has been blogging about her life since the birth of her daughter Lainey in 2007, weaving words and photography together to celebrate the small things in her family life in which she finds so much beauty.

In January of 2010, Kelle gave birth to her second daughter and learned that Nella Cordelia has Down syndrome. Her world was “rocked to the core” and she was sure life as she knew it was over. She was wrong—and Nella Cordelia is showing Kelle that life with an extra chromosome is amazing and beautiful, transforming her as a person and revolutionizing her photography.

“Beauty isn’t always where we expect it. And when we truly allow ourselves to look for it and find it, we are changed for good. My goal is to capture images of beauty in its purest form—not in the perfect outfit, the perfect pose, the perfect smile. No, that’s not what you want to remember. You want to remember what you see every day . . . real, raw beauty. Life happens everywhere . . . and it is beautiful. The true challenge is to bottle it up, and that’s what I do . . . with every little click of my shutter.”

Kelle lives in Naples, Florida with her husband Brett, his two sons, Austyn and Brandyn, their two daughters, Lainey and Nella Cordelia, and their son, Dash. She also regularly shares her family adventures on her Instagram account @etst.

Kelle Hampton Website

In July of 2010, Kelle received a National Down Syndrome Congress Media Award.

Photographer Matthew Day



Matthew Day has used photography to document subjects for over twenty years. He was first published by a major newspaper in 1996 when the Chicago Tribune used his images of women who volunteered as nurses in the Spanish Civil War. More recent projects include portraits of children living in a shelter and a close friend's battle with breast cancer, as well as photography of individuals with different chromosome conditions for projects at the National Center for Prenatal and Postnatal Resources.

"Although many people recognize photography as a purely creative endeavor, it is a powerful way to explore and create relationships that are uniquely human. It was many years before I learned that the reason I love taking pictures is because I love meeting new people and getting to know them on a level that you could never get to in a business setting or even a casual gathering of friends. In 2007, I was invited to photograph children with Down syndrome and their families in what was the first of other similar projects. There are many things an outside observer could say about what it must be like to raise a child with Down syndrome but what I always notice and feel the most is love."

Matthew Day's work can be seen online at matthewday.net and in the following:

Clear Margins www.blurb.com/b/564869-seeking-clear-margins

