



My sibling has Down syndrome...what does that mean?

**Sibling's Guide to Navigating Life
with a Brother/Sister with Down
Syndrome**

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What IS Down syndrome?

Down Syndrome is something that causes differences in the way a baby looks and learns. No two babies with Down Syndrome are quite the same, but they are often extra flexible, have eyes that slant upward, have small ears and a small nose, and grow more slowly than other kids. They also tend to learn more slowly than other babies. But every baby has his own personality and will look like other members of his family.

Stuve-Bodeen, Stephanie. *We'll Paint the Octopus Red*. Woodbine House Inc., 1998.

Why do some babies have Down syndrome?

Babies with Down syndrome are born with one extra chromosome in some or all of their cells. Chromosomes are tiny, thread-shaped things inside your body. They contain the directions that tell your body how to grow. These directions tell your body what color your eyes and hair will be, how big your nose will be, whether you will be a good singer, and many other things. When a baby has an extra chromosome, it mixes up his body's directions a little. That is why babies with Down syndrome look a little different from other babies and have to try harder to learn. Nobody knows why some babies are born with Down syndrome, but we do know that it is no one's fault.

Stuve-Bodeen, Stephanie. *We'll Paint the Octopus Red*. Woodbine House Inc., 1998.

Why are some grown-ups sad when they hear the baby has Down Syndrome?

Grown-ups might be sad because they did not plan to have a baby with Down syndrome. Sometimes they are worried because the baby might need to spend extra time at the hospital, or have to go back for an operation later. Grown-ups can also be scared if they don't know what to expect for their baby. It usually takes a little time for them to get used to their baby having Down syndrome, and then they can stop being sad and scared and just enjoy their new baby.

Stuve-Bodeen, Stephanie. *We'll Paint the Octopus Red*. Woodbine House Inc., 1998.

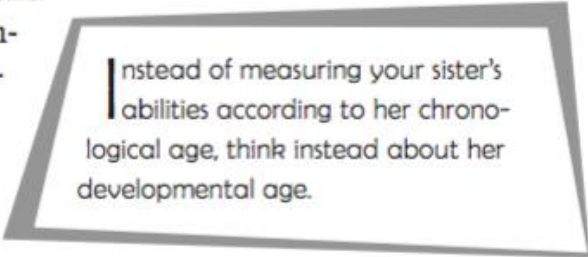
Will the baby be able to talk when he's bigger?

Like any baby, he will understand what words mean before he can say them himself. If he has trouble learning to talk, he might be taught to make signs with his hands to tell people what he wants. When he is older, he will learn to talk. He may not speak as clearly as other children. Brothers, sisters, and friends usually have no trouble understanding kids with Down syndrome.

Stuve-Bodeen, Stephanie. *We'll Paint the Octopus Red*. Woodbine House Inc., 1998.

Should I treat my sister like any other kid, or should I give her more of a break because she has Down syndrome?

Because she has Down syndrome, your sister is different in some ways from other people her age. She might have difficulty with following directions or understanding more complicated conversations. Consequently, thinking of her as slightly younger than her actual age might be helpful. Instead of measuring her abilities according to her chronological age (how old she actually is according to her birth date), think instead about her developmental age (the age at which she seems to be learning and understanding).



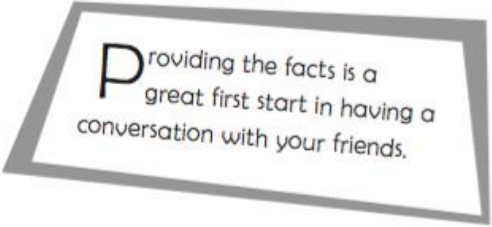
Instead of measuring your sister's abilities according to her chronological age, think instead about her developmental age.

In contrast to your other siblings or friends of her age, your sister might need to be repeatedly reminded of the rules or chores that need to be done. She might need to be shown how to do something several times before she successfully masters it. Your sister might need extra time to catch onto things. However, you and your parents should expect that she can follow the rules, behave reasonably, and have responsibilities around the house appropriate to her developmental age.

How do you figure out her developmental age? Your parents might be helpful with this. You can have a discussion about how much your sister understands and how you can best help her learn the rules. Your sister is certainly more like any other person than she is different. So treating her like one of the gang, who is just a bit younger, is often a good approach.

How do I explain Down syndrome to my friends?

Your friends are probably curious about Down syndrome, and some of them may not know very much about it at all. Meeting your brother or sister and finding out about his or her abilities



Providing the facts is a great first start in having a conversation with your friends.

and personal qualities will help to educate your friends. But, if they still have some questions, you can always share some additional information:

- Chapter 1 includes many facts about Down syndrome, including how it occurs and some of the common characteristics. Your friends might have a few other questions that are listed in that chapter. Providing the facts is a great way to start having a conversation with your friends. You can keep your answer short and sweet and change the subject if you don't feel overly comfortable with the discussion. As you get older and have more practice, you might find that you're more relaxed and at ease with any question.
- In addition to giving general facts, you might want to talk about your sibling's abilities and expectations for the future. Describe a few of his or her recent accomplishments or things that make you proud. Once you begin a conversation about Down syndrome with your friends, they will hopefully be more comfortable asking you other questions whenever they want to know more.

If you have **never** brought up the subject of Down syndrome with your friends, and now don't know where to start, take a closer look at the last question in Chapter 5 (page 118) for more ideas on how to start the conversation.

Siblings tell us that they are really good at communicating with their brothers and sisters who have Down syndrome. Since siblings and families spend more time together, we are often more familiar with each other. Often, siblings know what the expressions on each other's faces mean. They understand speech that other people may find difficult. Sometimes, siblings also learn sign language together.

Some things that might help you communicate with your brother or sister who has Down syndrome are:

- 1) Listen to what they are trying to say, and watch the movements they are making.**
- 2) Draw pictures of what you want to say, or expressions on faces, like a happy or sad face to show how you feel.**
- 3) Ask a speech and language therapist for ideas on how to communicate with your brother or sister who has Down syndrome.**

Siblings tell us there are lots of great things about growing up with a brother or sister with Down syndrome. Siblings often learn things like sign language, or first aid, or patience, or empathy and they feel proud about these new skills. Many of these skills will be really useful in life for being a good friend and good person, and also later in life when you're older.

Some things you can do to celebrate the good things:

- 1) Make a list of all the things you have learned to do as a sibling that other people your age might not know about.**
- 2) Give a presentation or speech to your class, group, or church about the skills you have learned through supporting and loving your sibling with Down syndrome.**

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Our Gentle Moon

by Amy Kivett Ogawa



Kaito, Yuzuki, and Mio Ogawa

I ALWAYS ENVISIONED THAT I would have the perfect family: my husband and I would have three healthy children, and they would be as close to each other as I am to my siblings. This vision became reality when my husband, Take, and I welcomed our first baby into the world. Although my main concern was having a healthy baby, I had secretly hoped for a girl, so I was thrilled when the doctor announced that we had a daughter.

It was tradition in Take's family for the grandfather to name the grandchild, so with the help of Take's father, we named her Mio.

meaning “endless beauty” in Japanese. We brought Mio home to our apartment in San Francisco on the evening of the Fourth of July. We could hear the fireworks outside and could see a blur of colors through the fog, but we weren’t interested in the holiday celebration. All we wanted to do was stare at our endlessly beautiful baby girl as she lay peacefully sleeping in her bassinet.

When we found out we were expecting our second, I once again hoped first for a healthy baby and again for a girl. I grew up with two older sisters and a younger brother, and although I am close with all of my siblings, I love the special bond I share with my sisters, and I wanted Mio to have that same experience. Our second would be two and a half years younger than Mio. In my mind, this was the ideal age gap between two siblings. And as luck would have it, our baby was due just a few months before my sister’s third baby. Her twin boys were less than a year younger than Mio, and I loved the bond she had already forged with her cousins. I couldn’t wait to meet the newest addition to our family and to watch the baby cousins grow and develop together.

When I was expecting Mio, my doctor recommended I have the full integrated screen to test for the three most common trisomies (13, 18, and 21). Although the results were “screen negative,” my doctor was concerned with the result for Down syndrome (trisomy 21), as it was close to the cutoff. I knew I would be in a state of constant worry for the remainder of my pregnancy, so I opted to have an amniocentesis. I lay in bed for two days after the procedure, afraid that any amount of movement could result in losing a potentially healthy baby. When we finally got the results, we were relieved: our first baby was going to be just fine.

Two years later, the options for prenatal testing had expanded. A handful of new companies with noninvasive prenatal tests (NIPTs) had entered the market. The sales pitch won us over: just a simple blood draw would let us know if our baby had the “correct” number of chromosomes. We opted to go this route in addition to having the standard integrated screen. Amniocentesis was no longer an option for me—I couldn’t handle the anxiety of an invasive procedure again, especially with a toddler to care for. The results from both

tests came back in the same week. Although the integrated screen was a “screen positive” for Down syndrome, the NIPT results were negative. Our doctors and counselors assured us that the NIPT had greater accuracy, so we put our trust in them and in the test.

As with our first pregnancy, we chose not to learn the gender of our baby prior to the birth. We loved the element of surprise and the experience we had when Mio was born and were looking forward to a similar experience with our second child. My husband carried the bins of Christmas decorations down to the garage and brought up the bins of Mio’s gender-neutral baby clothes in anticipation of our little one’s arrival. I washed and folded yellow and green onesies and selected an outfit with blue, green, and orange monsters to take to the hospital. We were ready—the bassinet was set up, the changing table was stocked with diapers, wipes, and all the essentials, and Take’s and my bags were packed for the hospital.

I went into labor early on a chilly morning in early January. We dropped Mio off at daycare and made our way to the hospital. It wasn’t long before our second arrived. “It’s a girl! We have another baby girl!” my husband exclaimed. My hope had become a reality: Mio would get to experience the same joys of sisterhood that I had. I was overjoyed in those few moments I got to hold our precious baby girl before the nurses whisked her away from me to clean her up and take her measurements.

As we were basking in our joy, one of the nurses delivered those devastating words: “We think your daughter has Down syndrome.” Heartbreak replaced joy, panic replaced calm, and all the hopes and dreams we had for our baby evaporated.



We sat in the hospital room paralyzed by our emotions—grief, anger, anxiety, and fear of the unknown. Is our daughter helpless? Will she walk? Will she talk? Will she go to school? We knew so little about Down syndrome, and all the stereotypes and stigmas were racing through our heads. Everything had been so easy with Mio—she

started speaking at such an early age and with such clarity that our attempts at sign language became irrelevant. She rolled over, crawled, and walked when she was supposed to. How was life going to be with a child with a disability? Would her quality of life be less than that of her sister? I wasn't cut out to be the parent of a special needs child. This wasn't in my plan for a perfect family.

My thoughts went back to the joy we had felt when Mio was born. We were so proud that we couldn't get the message out fast enough. In fact, we were so excited to tell friends and family about our perfect little girl that Take unknowingly misspelled her middle name when he sent the message. But with this baby, the situation couldn't be more different. I was ashamed and was not ready for the world to know that I had a baby with Down syndrome. I sent a message to my immediate family explaining everything and asking them to please keep quiet about her arrival. I received messages from friends checking in, and all I could respond was that we had a girl but the doctors thought something was wrong. I couldn't even bring myself to say the words "Down syndrome." The pain was just too great.

My parents and siblings got to the hospital as quickly as possible to comfort and support us. When my sisters arrived with Mio, I put on my best face for her and introduced her to her baby sister. My world was upside down, and Mio was my only sense of normalcy. I saw how she looked at her baby sister, completely unaware of her diagnosis and without judgment or sadness. Seeing how Mio looked at her, I realized that despite having Down syndrome, she was still just a baby and had all the same needs as a typical baby—she needed to be fed, held, and loved.

Naming our baby girl was the first step in our acceptance of her. Working again with Take's father, we decided on Yuzuki, meaning "Gentle Moon," as she was born on the first new moon of the year.



In the weeks and months that followed, Take and I leaned on each other and on our friends and family for support. We reached out

to various Down syndrome organizations in our area to learn as much as we possibly could about the effects this extra bit of genetic material would have on our daughter. The more we learned and the more we got to know Yuzuki, the more we came to realize that Down syndrome wasn't the end of our lives—it was just an unanticipated turn that would require strength, patience, and hard work.

Yuzuki is now three years old, and she is thriving. Although she struggles with activities that come so easily to her peers, her will and determination are unmatched. I watch her as she works in therapy day after day making slow but steady progress. She is fearless in her attempt to take on a new challenge. She has been an inspiration to us, and I often find myself thinking that if Yuzuki can overcome the obstacles that face her, then certainly I can get through my moments of adversity.

Yuzuki is a typical little girl in so many ways. She loves her baby dolls and her musical toys, and she enjoys going to the park. And like many three-year-olds, Yuzuki has tantrums, but most of the time she is energetic and full of life and love. She tries to take care of others even when she, herself, is still practically a baby. If other children nearby are crying, she tries her best to console them—hugging them, bringing them toys, or, in the case of her baby brother, bringing a bottle or pacifier. If her efforts fail, she too will start crying. This sense of caring and empathy is not something we taught her but simply a part of who she is. Her love for others is unconditional, and she, in turn, has taught us how to love unconditionally.

Although the relationship Yuzuki has with Mio and with her baby brother, Kaito, may not be the same as the relationship I have with my siblings, our three children share a special bond nonetheless. Mio has taken upon herself a role as Yuzuki's protector, and Kaito is her biggest admirer.

On a day-to-day basis, parenting Yuzuki is not much different than parenting Mio or Kaito. They all have the same basic needs and the same general routines. We do have a different set of challenges when it comes to Yuzuki. For example, communication can sometimes be a struggle, as she has just a few spoken words and a handful of signs. But parenting Yuzuki also has unique rewards. Each of her

successes is a cause for celebration, as we know she worked that much harder to get there. And whether she is accessorizing by wearing oven mitts around the house or trying to avoid going into preschool by climbing into the basket of her brother's stroller, she almost always manages to get a laugh out of us.

When Yuzuki was born, I thought that meant my perfect family had ceased to exist. I could not have been more wrong. I can't deny the pain I initially felt, but if I could go back, I would tell myself to enjoy every moment with her from the second she was born. I would tell myself to take more time to hold her and bond with her. I would tell myself that our Gentle Moon would meet many milestones and make us proud, and that she would inspire us, teach us, and fill us with love. And I would assure myself that our family is perfect the way it is.



Amy Kivett Ogawa lives in the Bay Area with her husband, Take, and their three children: daughters Mio (2010) and Yuzuki (2013, diagnosed with Down syndrome at birth), and son Kaito (2015). Between working as a program manager at a biotech company and shuttling her kids around to their various activities and appointments, she enjoys practicing yoga and traveling the world with her family in her "spare time."

Lynard, K. (2007). *Gifts*. Bethesda, MD: Woodbine House, Inc.

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Brothers

by Dena Castellano-Farrell



Garrett, Griffin, and Braeden Farrell

IT'S NEARLY DINNERTIME. I'm sitting in the living room, savoring the smell of dinner coming from the kitchen and smiling at my three boys. Garrett, age six, is leading his brothers in an energetic version of "Ring around the Rosy." Braeden, age five, is putting his heart and soul into the song as he teaches his little brother Griffin, age two, the moves. Griffin is giggling so hard just watching his brothers that he can barely stand up. "Ashes, ashes, we all fall down." The three of them collapse, and the giggling escalates. When Griffin stands up unassisted, you would think he just hit a grand slam.

Lynard, K. (2007). *Gifts*. Bethesda, MD: Woodbine House, Inc.

“Mommy! He did it!” his brothers chorus.

“Griffin stood up all by himself!”

“Way to go, Griffin!”

Of course I’m smiling; I am the luckiest woman on earth.

When Griffin was diagnosed with Down syndrome, I had so many worries about what this would mean for all three of my sons. Garrett and Braeden had just turned three and four years old. How could we manage this? I worried that we wouldn’t be able to give them enough attention because we would be devoting all our time to Griffin’s special needs. (I thought for some reason that Griffin would require round-the-clock care and our undivided attention.) I dreaded the seemingly inevitable neglect of their needs. I even planned ahead, teaching them at their young ages to write their first names, figuring I certainly wouldn’t have time to teach them once I was consumed with Griffin’s care. And as I envisioned the older boys’ futures, I worried that they would somehow be burdened with their brother. I imagined they would have to take over the role of parent to a grown child someday, sharing the responsibility of caring for Griffin.

I worried that our marriage was not strong enough for this. Sure, I always felt that we were happy, but this was something we had never been through as a couple. We had gotten through challenges before, such as unexpected job changes and parenting two boys born thirteen months apart. But could we handle all three of these brothers?

I also worried about how I would handle these difficulties on a personal level. Would I feel resentful of this child who would no doubt take up most of our time? Would he depend on us for the rest of our lives? In my darkest moments, I worried that I wouldn’t love him as much as his brothers because he wasn’t my idea of “perfect.”

Most of all, I worried about Griffin. Would he suffer? Would he be able to attend his brothers’ school? Would he be teased? Would he ever be independent? I cringed at the words “group home” when reading the literature from our geneticist, and couldn’t even utter the phrase without crying. I equated allowing him to live in a group home with sending him away to an institution; I couldn’t begin to fathom that situation.

Well, Griffin is now two, and my heart is much more settled. No problems with loving him—I'm totally smitten! And my fears about resenting him or favoring him have been laid to rest. We spend three hours a week with Griffin's therapists; one each for speech, gross motor skills, and fine motor skills. Part of their job is to show us how to incorporate his therapies into our family life. Whether it's chasing his brothers through a tunnel, letting them "read" to him, or teaching him the fine art of dumping water in (and out of) the tub, Garrett and Braeden are the best models and motivators Griffin could have. But we don't always make Griffin our focus. His three therapists understand that Griffin is not our only child and we shouldn't take away from our other boys for his sake. So Garrett and Braeden get their turns in the spotlight, too.

Griffin does not make us worry any more than our other boys. We no longer worry about his dependence; instead, we are planning for his independence. I no longer worry about his future; instead, I wonder about it. I used to think I knew what was in store for him. Now, I realize that I honestly have no idea. He might go to college. He might get married. He might live with us if he wants to—although, considering his desire to do everything his brothers are doing, I don't think he will.

Most importantly, his brothers adore him. They see him as any other little brother, sometimes annoying, sometimes getting into their toys. Yet they fight over who gets to help change his diaper (unless it's a stinky one). If Griffin needs or wants to live with one of them someday, arguing over who gets him may just tear them apart. But, I don't think that will be the case.

I think they will be competing to see who gets to be best man at his wedding!



Dena lives on the east coast with her husband, Christopher, and their three children, Garrett (1999), Braeden (2001), and Griffin (2004). Griffin was diagnosed with Down syndrome via amniocentesis twenty weeks into the pregnancy. Dena is an adjunct instructor in the math department at a local community college.

Lynard, K. (2007). *Gifts*. Bethesda, MD: Woodbine House, Inc.



According to research on siblings who have a loved one with Down syndrome, compared to their typical peers, “siblings are more compassionate and well-adjusted than their peers (Dykens,2005).”