



My grandchild has Down syndrome...what does that mean for my family?

A Grandparent's Guide to Navigating Life with a Grandchild with Down syndrome

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Facts about Down syndrome

- Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.
- There are 3 types of Down syndrome: trisomy 21 (nondisjunction) accounts for 95% of cases, translocation accounts for about 4% and mosaicism accounts for about 1%.
- Down syndrome is the most common chromosomal cause of developmental delay. One in every 691 babies in the United States is born with Down syndrome.
- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- There is a wide variation in mental abilities, behavior and physical development in individuals with Down syndrome. Each individual has a unique personality, capabilities and talents.
- A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all

What it means to be a Grandparent

Remember that it all begins with love. You love your child, who may now be facing parenthood a bit differently than they expected. You love your family and always want the best for everyone, for everyone to feel accepted and cherished. And of course you love your grandchild. This little one is first and foremost a baby, a sweet little child who needs to be held and fed and played with and loved. And in the big picture, what you will do to love your grandchild is much the same as you would do for any child.

You are not alone. There are many families with children with Down syndrome living in your area and our support groups welcome grandparents. By attending a family support group, you will have the chance to talk with others, learn more about Down syndrome and show support for your child (*the new parent*).

You are a role model. Being a role model in the love and care you show for your grandchild, and in the respect and love you practice for the new parents, will help other family members and friends have a positive approach to the situation and bring more support to the family. When the family and friends are supportive, everyone's life is elevated to a better place.

You are special in the lives of your grandchildren. The old expression, "Don't worry, you're in your Granny's!" means that when you are a child, you feel cherished and carefree when you are with your grandparent. Grandparents often have more time and patience to read books or throw a ball, to endlessly answer the question "why?" or have a tea party, to make up silly riddles or go to the park. That loving time builds a bond between grandchild and grandparent like no other.

Down Syndrome Association of Central California. "A Grandparent's Guide." 2007. Accessed 23 September 2019.

Developmental Milestones

Milestones	Child with Ds	Typical Child
<i>Gross Motor Skills:</i>		
Sitting Up	6-30 months	5-9 months
Crawling	8-22 months	6-12 months
Standing	1-3.25 years	8-17 months
Walking	1-4 years	9-18 months
<i>Language Skills:</i>		
First word	1-4 years	1-3 years
Two-word phrases	2-7.5 years	15-32 months
<i>Personal/Social Skills:</i>		
Smile	1-5.5 months	1-3 months
Finger feeding	10-24 months	7-14 months
Drinks from a cup	12-32 months	9-17 months
Using spoon/fork	13-39 months	12-20 months
Bowel control	2-7 years	16-42 months
Dressing unassisted	3.5-8.5 years	3.25-5 years

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How can you, as their grandparent, help?

- **Educate yourself** on Down syndrome as much as possible. The better you understand the situation, the more you can help to embrace this wonderful new child.
- **Show your full support.** Be sure to make sure they know that their child will be welcomed and loved and that you will be there for them.
- Make sure **you are being sensitive to your child's feelings.** It is normal for there to be a lot of conflicting feelings such as joy and sadness, or fear and hope. Be patient and comforting towards these confusing feelings that the new parents are experiencing.
- **Show your acceptance** of your new grandbaby. Human touch is very healing and a large part of the development of infants. Be a part of the progress your grandchild can make through touch and offer to hold and love on the new baby.
- **Remember to give attention to your new grandchild's brothers and sisters.** It is common for siblings to get lost in the shuffle after the diagnosis of another child. Call them often just to talk and consider bringing a special gift to them.
- **Ask how you can help.** Often times new parents think they have to do everything themselves. Offer help where you can and make sure your child knows that you are there for them.

Phrases to avoid...

There are certain phrases that we often say to individuals going through a difficult time. While these might feel like the right things to say, they may have more of a negative impact than a positive impact. In order to be aware of your loved one's feelings during this difficult time, try to avoid the following:

- **“I’m sorry” or any pity.**
- **“Special babies are for special parents”**
- **“They are all so loving”**
- **“Down syndrome is no big deal”**
- **Cards that resemble sympathy cards**

While all of these are usually said out of love and concern, expectant parents sometimes hear things that aren't intended because of the mix of emotions they're experiencing.

Iannone, N. M., Meredith, S. H., & Geoffroy, A. (2015). *Your Loved One is Having a Baby with Down Syndrome*.

Grandparents can make a big difference

Playing games to help your grandchild communicate

A big part of inclusion is the ability to communicate with others. For children with Down syndrome, this can be challenging and it may take some time for them to be able to physically say words. Think of how frustrating it must be for your grandchild to want to tell you a story or ask for something, but to not be able to make you understand. But the good news is that you can help, you can make a big difference in the communication skills and vocabulary of that child.

Things you can do today:

Learn Baby Sign Language

Simple sign language can help your grandchild express themselves before they can physically say the word.

Teaching them to sign will be a great bridge to spoken words and help everyone feel less frustrated.

There are many DVD resources that you can watch with your grandchild to learn simple signs together. Make a game of it and you will both benefit.

Narrate the World

As you go about your daily chores and errands, point out objects and say the word then ask the child to repeat the word.

Even emotions or concepts can help vocabulary building. See a baby crying? Say “sad” or “mad.” At the playground? Say “up” at the top of the slide and “down” at the bottom!

Use “Total Communication” Methods

Total Communication (TC) is an approach to education that aims to make use of a number of modes of communication such as signed, oral, auditory, written and visual aids, depending on the particular needs and abilities of the child.

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A GRANDPARENT'S STORY

by Beverly Beckham

A CHRONOLOGY OF EMOTIONS

I will have to apologize to her someday. I will have to tell my grandchild that I cried the day she was born.

Not immediately. Not when I first held her and she looked into my eyes and I looked into hers. There's a picture of this. Lucy, just minutes old, almost saying hello. I never shed a tear in the first 12 hours of her life when I thought she was USDA-approved-top-of-the-line perfect Grade A baby girl. Then I was all smiles. I called my friends and said the baby has come. Lucy is here. Lucy is perfect - round cheeks, red lips, downy skin, blond hair, blue eyes.

We joked with her father. We all hugged one another. We were so lucky. We got our miracle, we exclaimed. And there was no doubt that we had.

And then a doctor walked over to the bed where Lucy lay and he unwrapped her and inspected her. And he said the word test. And then he said Down syndrome.

Iannone, N. M., Meredith, S. H., & Geoffroy, A. (2015). *Your Loved One is Having a Baby with Down Syndrome*.

We cried then. All of us. Instantly. Because what had been perfection just seconds before, what had been all joy and gladness and light, became, with two little words, imperfection and fear.

Stupid, stupid us.

How will I tell Lucy that we wept while holding her? How will I explain that in those first few hours we looked at the gift God created just for us and wanted Him to make it a better gift? To fix it. To make our little Lucy just like everyone else. There's been some mistake, God. This isn't what we prayed for.

But isn't it?

Give us a baby to love, we begged, and we have her and what sweeter, better, bonnier baby could there be?

People told us that it's only natural to grieve the loss of a dream. And that's what I like to think we did. We dreamed one Lucy, the perfect little girl - like Margaret walking with her mother, like Shiloh on the stage in her toe shoes.

In those first few hours it was this dream that tormented us. And it blinded us, too, because all we could see was what Lucy wouldn't be. Here she was, infinity in our arms, fresh from heaven, in such a hurry to get to us that she arrived two weeks early. And we were judging her.

She left the angels to come here. She gave up Paradise for us. And we cried.

Funny thing is she hardly cried. She opened her eyes and took us in, one at a time, and amazingly she didn't seem disappointed at all.

One in 800 babies is born with Down syndrome. The rarer the jewel, the more value it has. That's the way it works with things - with pearls and Lottery tickets and horses and art.

But in our world and in our culture, we like our people to be all the same.

How will I tell her that I wanted her to be just like everyone else? That I was afraid of different when it's what's different that stands out? Are the black sand beaches in Hawaii sad because they're not soft and white? Do four-leaf clovers ache to be three? Does the life that grows above the tundra wish it were rooted in a valley instead?

The red rocks of Utah. Icebergs. The Lone Cypress. The Grand Canyon. And Lucy Rose.

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We expected our life with Lucy to be lived on paved highways with well-marked signs, the rest stops never far from one another.

Lucy is taking us down a different road, a blue highway, instead. It's scary not knowing what's ahead. But no one, even on the wide smooth roads, knows the future.

We yearn for paradise. Lucy just came from there. She is heaven in our arms. We didn't see this with tears in our eyes. But we see it now.

FROM LUCY, A FULFILLING YEAR

It's one year later. One year after the ground caved in and the world blew apart and the center failed to hold. One year after we were told, "I'm sorry" so many times that we were sorry, too.

Three hundred and sixty-five days, some of them terrible. The day my granddaughter Lucy Rose was diagnosed with Down syndrome. The cold, rainy day she came home. The day the doctor said she needed heart surgery. The day of the surgery when the operation didn't go as planned. The days after, at the hospital, when we felt helpless at her side.

So many days at home, holding Lucy, begging, "Hang on, little girl. Don't leave us." Winter closing in, doors closing everywhere.

More surgery. More problems. Hope frayed.

Fifty days? 100?

We clung to each other - mother, father, grandmother, grandfather, aunt and uncle. It'll be OK, we said over and over.

And when we didn't believe this anymore, friends came and took our hands and kept us from drowning in sorrow and fear.

We worried Lucy would die. We worried she would live and not know us, live and not respond, live and not see, not hear.

We worried about everything.

We still worry. But not the way we used to. We're standing on solid ground, for now anyway - and now is all any of us has. Lucy is healthy and happy and is turning a year old Sunday. And we know, because of this year, just how lucky we are.

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We ask ourselves, why did they shake their heads when she was born? Why did they say "We're sorry" and not congratulations? Why even now do doctors say, "We have tests. This won't happen again," as if Lucy shouldn't have happened. As if they would erase her if they could.

Erase the heart problems. Erase the need for surgery. But don't erase Lucy.

Lucy is like a crayon Crayola has yet to invent. So many colors - burnt sienna, maize, mulberry, raw umber, razzle dazzle rose.

But no Lucy Rose. Because she is the color of wind. The color of moonbeams. The color of stars that are too far away to see.

She is rare and she is different and she is beautiful and bright and we have been blessed because she is ours.

Before she was born, I talked this prayer to her. "Throughout life you will be both a student and a teacher, for you have much to learn and perhaps even more to teach."

I imagined teaching her "Pat-a-cake" and "This Little Piggy" and the names of things. And I have done all this.

What I never imagined is what she would teach us.

The children will lead you. And she has.

Lucy has led us through the toughest of times. The ground caved in, the world blew apart and the center failed to hold.

But Lucy endured. And grew stronger. And thrives.

And because of family and friends, so do we.

We held her so much. Maybe that's why some of her rubbed off, some of her joy, her good nature, her smile, her pluck.

When I was in second grade, Rosemary, the most popular girl in class, picked me to be her best friend. We walked arm in arm. We sang. She invited me to her house. We had fun all the time.

That's how it is being with Lucy.

All children bring joy. Lucy brings something more. Maybe that's because we came so close to losing her. "Eat, baby." "Look at us." "Say Dada." "Go to Mama."

And she did.

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And she does.

And life is good.

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