



* 21
Welcomes



Canadian
Down Syndrome
Society

Société canadienne du
syndrome de Down

Welcome

We're So Happy You're Here!

Congratulations on the arrival or expected arrival of your new baby!

Having a new baby is exciting, but it can also be overwhelming and a little bit frightening to find out your child has Down syndrome. The Canadian Down Syndrome Society (CDSS) is here to support and encourage you through all the ups and downs of having a loved one with Down syndrome. We hope *21 Welcomes* supports you through the beginning of your journey in the Down syndrome community. It will also help you educate your friends, family, and other community members about what it is like to love a person with Down syndrome.

Throughout this book you will find information about:

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More importantly, you will find stories and quotes from other parents, grandparents, siblings, and self-advocates (adults with Down syndrome). Many new parents find it comforting to connect with a story similar to theirs, so we hope that you find these helpful as you get to know your new, beautiful baby.

If you read through this and feel that you still need some more information, please feel free to contact our office at 1-800-883-5608 or by email at info@cdss.ca. Extra information is also posted on the New Parents section of cdss.ca.

We are so happy to welcome you to this new community. We hope that this package helps you feel connected in a time that may be isolating. Although you might not be ready for it, there is a huge group of amazing people ready to greet you with open arms. Read about some of them in the pages to come.

“The majority of parents felt that their outlook on life is more positive because of their son or daughter with Down syndrome.”

– DR. SKOTKO et al.

DR. BRIAN SKOTKO is a Board-certified medical geneticist and Co-Director of the Down Syndrome Program at Massachusetts General Hospital. He has a sister with Down syndrome who has given him invaluable experience in the Down syndrome community. Dr. Skotko has dedicated his professional energies toward children with cognitive and developmental disabilities. In 2001, he co-authored the award-winning book *Common Threads: Celebrating Life with Down Syndrome* and, most recently co-authored, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*.

Throughout this book, you will find some excerpts from his research with Susan P. Levine and Richard Goldstein in purple boxes, like the one to the left.

21 Welcomes

21 Welcomes represents the 21 stories from parents, siblings, grandparents, and self-advocates featured in this book. These Canadian Down Syndrome Society members share their honest perspectives on being welcomed into the Down syndrome community.



Société canadienne du syndrome de Down

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Dear New Parents

BY PAUL SAWKA

Dear New Parents,
Congratulations on the birth of your baby!

It is okay to be a bit sad and scared, but I hope by telling you about my life, you will feel better. My name is Paul, I have Down Syndrome and I am the Awareness Leader at CDSS. I have a great life and I feel very proud of it. It is important as a parent to have high expectations and to give lots of support to your child. Growing up, I had a lot of support and love from my family.

When I was young, I played sports and went to school. I learned math, reading, writing, and singing. I had a lot of fun learning and growing. I went to many schools and enjoyed them all. After high school I went to Mount Royal University and Columbia College. I went to university because I want to learn the things that I would need to get a job in the future. I did learn many important skills that helped me get many different jobs. I was also valedictorian at my graduation from Columbia College!

I live in an apartment with a supportive roommate. I am able to get to work on my own. I am independent—I have some help, but I'm able to do lots of things on my own. Having Down Syndrome did not stop me from doing all the things I have wanted to do. If you want to know more about me or have any questions about people with Down Syndrome, please check out my blog at www.cdss.ca/paul/

All the Best,
Paul Sawka
CDSS Awareness Leader



Dear Lucky Ones*

BY TARA McCALLAN

(* You may not feel lucky yet)

If you are reading this letter you, somehow, someway, are on a similar path that I've walked. A path that, maybe, probably, wasn't one you wanted to go down. A path that looks terrifying, uninviting, and not at all what you expected.

If you are reading this letter you have a baby with Down syndrome.

When I found out I was having a little girl, I let my dreams build up, my expectations soar, and my mind ponder all that she would be. Then three days after she was born, a doctor looked at me with the saddest eyes possible, eyes that will forever haunt me, and said, "I'm sorry to be the one to tell you this, but your daughter shows many signs of Down syndrome."

Wham-Bam-Slam-Slap! Right across the face—that's honestly what it felt like, as I was utterly stunned. Everything I ever hoped for my daughter, for my little family, for our life together, seemed to die in that moment. It was as if in his words, that doctor took the entire happiness out of our new baby.

I've never wept like I did in that hospital bed. I've never cried for something I wished wasn't true so hard—I've never begged fate to undo what couldn't be undone. I was literally shattered in devastation.

The following few days were a whirlwind of medical appointments to rule out other complications associated with Down syndrome. I couldn't tell you one thing the doctors said during that time. My mind was in such a weird space, almost as if I was in the room but not truly believing that this was even happening, that this was our life, that this was our daughter.

But a fierce, protective love was growing inside of me even though I didn't know it. In one appointment with a genetics specialist and a counsellor, my mind drifted as they talked about the makeup of chromosomes, FISH test and a wide variety of spectrums, until the doctor said, "For your next baby, we can do testing and prevent this."

Right there, a few days after our daughter Pip was born, the tone of how people, doctors, and others would value her life was set. In a way, that kind of made me love her more.

Because, you see, that genetics specialist doesn't know what I now know. A diagnosis can't predict the extraordinary love you will



have for your child. A genetic counsellor can't understand the fierce value you place on your baby's life. A friend might not realize that your baby is an individual made up of so much more than a diagnosis. A stranger can't possibly know the outrageously beautiful insight you get to experience by seeing life through the eyes of someone with Down syndrome. An extra chromosome doesn't mean the end of what you imagined. It almost means a life more beautiful than what you ever could envision.

But it takes time to get there; this path of ours is meant to be different. It is okay to take time to grieve what you envisioned in a child—from that you will grow. And my hope for you, friend, is that from this grief you will then blossom. You will find your own way, glimpses of hope, moments to celebrate, tears to shed, anger to let go of on this journey.

For my husband, the meetings with the doctors, the New Parent Package from the Canadian Down Syndrome Society, and reading as much information about Down syndrome as he could, helped. For me, it did not. I wanted what doctors, organizations, and articles couldn't tell me. I wanted a look inside other parents' lives, perspectives on how it all has changed them, and what to expect.

While I was scared to look, and to discover what I feared, I was instead pleasantly surprised. The more I looked, minus what Google or Wikipedia said about Down syndrome, the more I discovered what a unique and special diagnosis this really is.

For me, one of the hardest things after finding out Pip had Down syndrome was telling people. I didn't know how to do it, how to react to strangers, what to say, what not to say. So I started by sitting down one night a few weeks after Pip was born and through tears, wrote out some pretty raw and emotional thoughts on her diagnosis—and from there my website Happy Soul Project started.

But it's one thing to share your thoughts behind a computer and another to be out in the world. A moment that really changed things for me was when Pip had her first surgery at five weeks old. I had only written about Down syndrome on Happy Soul Project. So on this fated day I was down in the hospital gift shop and an older lady behind the counter asked why I was there. I explained Pip's surgery and added, "and she has Down syndrome." It was as if by finally saying it out loud, I had accepted it.

The lady dropped everything, came around the counter, grabbed my shoulders, looked intently in my eyes and said "You are so lucky," for which of course, I thought she was crazy. Here I was scared to say it out loud, unsure of how to tell people, almost embarrassed because of it, and she was telling me I was lucky. She went on to explain through genuine tears that she had a brother with Down syndrome and it was the absolute best thing in her life. It made her who she was and kept her entire family together. He was the joy the world needed and that I was so lucky to have that.

Fearing an "I'm sorry"-type comment, only to be given the exact opposite, changed how I viewed a Down syndrome diagnosis and how I will respond to any new parent moving forward.

In that moment I realized she was so absolutely right. I had been looking at it all wrong. I thought I needed to learn to accept my daughter for her differences, when really I needed to learn how to celebrate and be blessed by them.

Changing my perspective has changed my life and, I'm sure, the life Pip is going to have. Now it's my mission to prove to the world that we really are the lucky ones. That is what now fuels Happy Soul Project: to show others that the unnecessary, negative stigma behind a Down syndrome diagnosis needs to change.

I wish there was a way I could go back and save all those tears I shed when I found out Pip had Down syndrome. But I also think that grieving the loss of what I had envisioned for our future gave me the room for expecting the unexpected. Pip is not what I thought I wanted in a daughter until I realized I never knew I needed this kind of love.

So with that, take this letter as if I'm shaking your shoulders like that lady did to me. Actually, I'm wrapping my arms tightly around you, I'm holding you tight as you cry, scream, and work through your grief, begin to see the beauty in the path you've been chosen to walk and letting you go to smile at you and welcome you to the club, my friend.

We're the lucky ones...

Love,

Tara (Pip's momma)
Happy Soul Project

*"A diagnosis
can't predict the
extraordinary love
you will have for
your child."*



About Down Syndrome

Down syndrome is a naturally occurring chromosomal arrangement that has always existed and is universal across racial, gender, and socio-economic lines. One in every 781 babies born in Canada has Down syndrome. Down syndrome is associated with chromosome 21 and there are three types: Trisomy 21, Translocation, and Mosaicism.

TRISOMY 21

95% of people with Down syndrome have Trisomy 21

Cell division results in three copies of chromosome 21 instead of two

TRANSLOCATION

2-3% of people with Down syndrome have a translocation pattern

Part of chromosome 21 breaks off and attaches itself to another chromosome (often chromosome 14)

Two-thirds of translocation occurrences are spontaneous, while one-third is inherited from a parent

MOSAICISM

2% of people with Down syndrome have Mosaic Down syndrome

Cell division occurs in one of the early cell divisions after conception, resulting in some cells having three copies of chromosome 21 instead of two



The effects from the extra genetic material vary from person to person, and the degree of resulting developmental delay also varies.

Forty percent of children with Down syndrome are born with a heart defect. Many of these heart defects repair on their own, while some require surgery to correct the problem. Doctors will often check your baby's heart for this. Babies with Down syndrome also have low muscle tone. This is known as hypotonia, and is nothing to be concerned about. Parents have often described this by saying their baby is extra-flexible.

Although people with Down syndrome often share some features such as almond-shaped eyes, a single palm crease, and small ears, this varies greatly between individuals. Individuals with Down syndrome will look like their family members and will have their own unique personality.

People with Down syndrome are not all alike. A popular generalization is associating people with Down syndrome as always loving, smiling, or happy. Just like the general population, people with Down syndrome experience a full range of emotions. There is more to your baby than Down syndrome. Your child will have their own personality and you will start to see their personality grow and develop as they do.

*"A baby is designed by love.
Learn what to expect when you are expecting.
Don't let the information scare you.
Above all, love your baby, no matter what,
and he or she will love you back."*



– NICK POPOWICH

A Hero In Many Ways

BY WILLIAM MORIN

I was preparing decades earlier, before Wii'um came into this world, without knowing it. I studied sign language in college and researched learning styles for native children while in university. Before Wii'um was born, growing in his mother's belly, I would sing and drum to him in Ojibway. On days when I came home late, from within the womb he would lie still until he heard my voice.

When he was born, we were overjoyed by his arrival but worried for his health as he was small and required many machines to keep him alive. Within a week of his birth it was confirmed he had Down syndrome. My wife and I embraced each other in shock, but we were also comforted by our traditional Anishinaabek teachings, that every child is a gift and teacher. With the support from our culture and family, we cherish every day which reveals a new discovery of Wii'um's gifts and what he has to teach us.

We provided Wii'um with stimulus daily through mountains of books and objects of various sizes together with the freedom and space to discover his environment. This revealed to us his way of communicating to the world. He loves patterns, shapes, colours, and is quick to recognize differences and variations. He could sit for hours organizing shoes in decorative and elaborate patterns.

He is a brilliant mimic, echoing what you say and do with a desire to assist in baking, dishes, cooking, and raking leaves. Books consume so much of his quiet time before bed and early in the morning. He wakes up covered in layers of all his books. He loves being told stories and engaging in the stories, acting them out. We have read to him since he was small. When his little brother M'komii was first brought home, Wii'um quickly ran to his room grabbing "Bedtime Stories" and attempted to read it to M'komii.



As a big brother with limited vocalization, Wii'um is a true role model for his little brother. He inspires and motivates M'komii in all levels of play and activities, using everyday items to create innovativeness and technicalities beyond our expectations. Wii'um taught his brother basic sign language at an early age, which in turn enhanced M'komii's intellectual development.

Wii'um is a very well-known and respected traditional dancer at pow-wows in Northern Ontario. He is fearless in the dance arena in all dance styles, which he does with humility to the admiration of veteran dancers. The older he gets and the more he develops his personality and passion, the more he will flourish into the unique person with a passionate soul that he is.

Miigwetch / Thank You.

William Morin

Wii'um was named a "Canadian Down Syndrome Hero" in 2014.

Love Is What We Are Born With

BY VALERIE TIH

We were full of love when we first met Tyler. He was born "en caul", or in his amniotic sac, and we later learned that this is extremely rare (estimated one in 80,000 births). In some cultures, a child born "en caul" is considered to be destined for great things.

Our Tyler is almost three years old. He is a welcome and active member in his preschool class. He loves swimming, music, and playing with his big brother. He enjoys climbing, swinging, and sliding at our local park. He can proudly identify all the letters in the alphabet, read you some words, and he has even started writing his name. He makes our heart sing. We delight in seeing him grow and change.

If I could go back in time, to the moment we received our son's diagnosis, this is what I would have told myself:

Valerie, you are going to stretch and grow in incredible ways. You are going to become a better person. Trust your inner wisdom. There is more than one way to raise a typical child, and raising a child with Down syndrome is no different. You are up for the task!

If something doesn't sit right, get a second opinion. Try not to hang out in fear of the future. Stop focusing on that laundry list of potential medical issues. Instead, come back to the present moment. Your son is more than this diagnosis. He will have hopes and dreams, just like everyone else. He will delight you and everyone he meets. Get to know your son and start right now!

What you are feeling is natural and normal. Be gentle with yourself. There will be some bumps and worries along the way, but that's just part of parenthood, period. There are lots of parents who have walked in your shoes and they are happy to support you. You are about to be part of a club that you never expected to be part of—get ready to meet amazing people and to make new friends.

Tyler reminds us, and those closest to us, to look a little closer and to recognize that everyone is innocent and made of love; we just forget all the time. Tyler helps us to prioritize what is important:

Slow down, stay in the moment, and connect to love.

Tyler has taught us to see that everyone has unique gifts to contribute, and to appreciate and advocate for diversity. Tyler's light shines brightly and effortlessly, which gives others permission to show up bravely and authentically too. So to my husband and me, Tyler is already living his destiny of "greatness" because he inspires us to live Marianne Williamson's words, "Love is what we are born with. Fear is what we learned here. The spiritual journey is the unlearning of fear and the acceptance of love back into our hearts."



Talking About Down Syndrome

It's important to use appropriate language when referring to any group of people. Correct terminology helps reduce prejudice, misconceptions, and stereotypes. This guide will help you when talking about Down syndrome.

IT'S "DOWN SYNDROME"

Down syndrome is named after Dr. John Langdon Down, the first person to identify Down syndrome. He didn't have Down syndrome, so it is not possessive (as in Down's). However in some parts of the world it is still appropriate to use "Down's."

USE PERSON-FIRST LANGUAGE

A person should not be defined by their disability. Emphasize the person. It's not "Down's kid." It's not "Down syndrome person." It's "person with Down syndrome."

BE POSITIVE

A person is not "suffering from" or "afflicted with" Down syndrome. A person "has" Down syndrome. People with Down syndrome can lead fulfilling lives—they can go to university, get married, and have careers!

END THE R-WORD!

The r-word is often used in every day speech in a derogatory, offensive, and hateful way. If you stop using it, you help promote the acceptance of people with all disabilities, including Down syndrome.



***"We need
diversity, it's
how we learn...
We learn from
each other."***

– MICHELLE PONICH
(Sibling Advocate)

Everything Is Possible

BY CRYSTAL TRUMPER

Welcome! You are now officially members of the club we like to call “The Lucky Few.” You may feel like you were forced into this club and don’t want to be here, but hopefully you will soon realize it’s a great one to be part of. Membership perks include: extended snuggles, celebrating every single milestone, beautiful almond-shaped eyes that will take your breath away when you least expect it, and the knowing smiles from strangers on the street that act as our secret handshake—they’re part of the club too and just want you to remember that you’re never alone.

If I can give you one single piece of advice, it is to make this your mantra: Everything is Possible.



Here is where I have to let you in on a tiny secret: Lily is adopted. My wife, Jessica, and I knew that we always wanted to build our family through adoption and we have a background of working with people with special needs. When you choose adoption there is a list of questions that a social worker goes through, asking about the “type” of child you would be willing to bring into your home: a child who has witnessed violence or neglect, a child exposed to drugs or alcohol, etc.

Those ones were tough for us, because we pictured an unknown future and it was terrifying. For us, the question, “Would you accept a child with Down syndrome?” was the easy one because it was a world that we already knew and far less intimidating than the complete unknown.

This is where I commend you. Joining this club is so different for every single person and maybe this is your scary unknown, but you’re here. If you’re here, then you’ve taken the first steps to face the scary and embrace the adventure. Perhaps you’re having trouble imagining what life is going to look like in two weeks, or even five years down the road, but the fact that you’re trying to picture it is a great start. Try to remember not to compare—no two children are the same, not even two children with Down syndrome.

Lily, like many other children with Down syndrome, also has a congenital heart defect, which at seven months old led to a cardiac arrest and a brain injury that caused her development to restart. We’ve been playing catch-up ever since. At five years old, she’s just beginning to walk with the help of a walker or some guiding hands and is now working on how to communicate with us through more than just giggles or tears. For two people who thought we knew all about the road we had chosen, we suddenly found ourselves facing the complete unknown.

There are days that the road has seemed long and impossible; days when we’ve sat her down beside her peers and almost cried seeing how far apart they were in their skill levels. It’s so very easy to watch two children playing side by side and get overwhelmed at the differences. Those are the times that we’ve needed to remind ourselves of our mantra—everything is possible.

In our house, we call it “Lily Time.” We use it to remind ourselves that Lily will do everything; she will walk, she will talk, she will dance and she will sing, as long as we allow her to do it in “Lily Time.”

I’m not saying to ignore the voices of the therapists and doctors who are helping you along the way. I’m just suggesting that sometimes you need to throw away the charts and the calendars and just watch. Take the time to look backwards and see how far you’ve all come since the day you first joined this club. Choose to celebrate that instead of trying to figure out what comes next. For the number of days that we’ve felt frustrated, there have been hundreds more filled with giggles and hugs, days filled with an absolute pure joy at being part of a club that truly allows you to witness that “Everything is Possible.”



A Whole New Wonderful

BY MARY & ED CASAGRANDE

Dear new parent/parent-to-be,

We want to start off by saying congratulations. You may not know it yet, but you're embarking on a one-of-a-kind adventure that will truly change the way you look at life, people, happiness, and love. We know how difficult these early days of finding out your child's diagnosis can be. We were there too, at twenty weeks pregnant and feeling like the world was crashing down around us. We didn't think we would be strong enough to be parents to a child with special needs. You will surprise yourself by the strength you have within yourself and the abundance of love you will feel for a child whose diagnosis may have initially brought you so much sadness and grief.

If we had known how beautiful life would be with our daughter Emma in our family, if we had known how much happiness she would bring to everyone around her, we would have shed a lot less tears back then. If we could have fast-forwarded and seen what a beautiful relationship our son has with her, we would not have grieved for him not having a typical sister.

Emma's smile can light up anyone's day, her giggle is contagious, and her perseverance inspiring. Her beauty radiates both inside and out. We feel so incredibly blessed to have her in our family.

Go through these steps of grief you are currently feeling. It is important to allow yourself the time to heal from the loss of the expectations you had of having a typical child. Letting go will allow you to make room in your heart for a whole new wonderful that will surprise you.

Sincerely,
Mary & Ed



“You will surprise yourself by the strength you have within yourself.”

Adjusting

After finding out your child has Down syndrome, you may experience a wide range of emotions. This is normal. There is no right or wrong way to feel.

Receiving the news can be shocking. You may be feeling a lot of emotions at once. It may take time to adjust to your child having Down syndrome. This is okay. Your journey will be unique to you.

All parents have different feelings when they find out they have a child with Down syndrome. Some parents feel happy and excited about the birth of their baby, while some experience feelings of shock, sadness, guilt, or disappointment. Many feel a lot of uncertainty and doubt regarding their child's future. All of this is normal. You should know that there is absolutely nothing that you did to cause your child to have Down syndrome.

“Can we all please stop pretending that we’re all ‘doing great’ all the time and actually say ‘I’m miserable’ sometimes and then get on with our day anyway?”

– ANONYMOUS PARENT

No matter how you feel, remember that you are not alone in this journey. Your partner, other children, and other family members may be experiencing feelings and emotions similar to yours. If you are comfortable with it, talking about your feelings with family and close friends may be helpful for everyone.

Adjusting takes time. The adjustment process is different for every person. You should take as much time as you need in your journey toward acceptance. Finding support in your family and from other parents who have a child with Down syndrome can be helpful.

Right now, you probably have a lot of questions and concerns. Try to surround yourself with friends and family who will support you through this time. Finding a strong support system will help you with some of the challenges that might be associated with raising your child. If you feel like you are not able to cope, seeking help from a professional may be beneficial.

When you are ready, contact a local Down syndrome organization in your area. This will help you get involved with support groups and meet other parents and families who have a child with Down syndrome. Many parents find connecting with other parents of children with Down syndrome an excellent way to share feelings and concerns and to gain resources. Talking to other people who have gone through similar experiences might help you feel less alone and give you hope for the future.

If you aren't ready to connect with other parents, that is okay too. Feel at peace with your adjustment process. If you would rather read about others' experiences, a blog might be a good start. There is a huge community online, and our website has some great recommendations on where to start!

Remember you have just had a new baby and that is something to celebrate. Having a child with Down syndrome does not mean your child won't bring you and your family joy and happiness. Your baby just needs to be loved like any baby does.



“

“You already see the ability in your child, you just have to see it in yourself.”

– CRYSTAL TRUMPER

”

I Will Always Love You

BY KRISTA ROWLAND-COLLINS

We found out about Adele's diagnosis when we were fifteen weeks pregnant. It was a difficult time for us, with emotions running on high. Our minds raced. Our doubts took over. Our hopes of having the perfect child shattered right before our eyes. We thought that the perfect child would be one without Down syndrome. How could we raise a child who has special needs? Our thoughts were so clouded by statistics, it was overwhelming and disheartening. We were facing the unknown. Emotion had taken over logic, we needed to grieve.

We went for our eighteen-week ultrasound and saw this perfect little miracle, flailing her arms and legs and bouncing all around. She was ours. She was our baby. She wasn't Down syndrome. We fell madly in love with this little being whom we had not even met.

Today, we have a beautiful baby girl. We see this little being, a human life that is capable of so much. There are no limits for Adele; there are hopes and dreams, support, love, and encouragement from the world around her.

When I look into Adele's eyes, I see strength, courage, and love. I see right into her soul. I see this beautiful angel who has impacted many lives in such a short period of time. I see that she has changed so many views and she has done this not only in our home town, but all across the world because of social media. She has brought so many special people into our lives. I love her for doing this. She has made me a better person. My child has taught me the value of diversity. She has taught me that having an extra chromosome has made her one extra-special little girl. She has taught others that love is unconditional.

Adele has encouraged others to find out more about Down syndrome and has shown so many just how resilient and beautiful she truly is. So beautiful.

I am your mommy Adele. I will always look after you. I will always love you. I will always lead you in the right direction. I will always show others that you came into this world for a reason. You have this diagnosis for a reason. You are a miracle!



Modern Nest Photography

Because of Adele...

Our family has started a project called Adele's Over the Rainbow Baskets – Down syndrome LOVIN. Through donations from the community, friends, and family, we are able to make baskets for families who have a baby born with Down syndrome in the Calgary area. The baskets are filled with lots of items for baby and for the family, including a list of resources for the family to access once at home with their bundle of joy. Our goal is to bring comfort and joy to families, and to let them know that there is support, and that there are others on the same journey.

Sharing The News With Your Friends & Family

After learning your baby has Down syndrome, one of the hardest things can be telling your friends and family. You may still be in shock or adjusting. You may be worried about how others are going to react to the news. It's normal to feel nervous about telling your friends and family that your baby has Down syndrome.

Before sharing the news about your baby, it is helpful to have an understanding of Down syndrome. When telling your friends and family, emphasize that a new baby is something to be excited about and celebrate. A great way to share the news of your baby is to send out a birth announcement. In addition to the usual birth announcement details, you can include a few facts about Down syndrome, and maybe a video that you'd like to share. You can find some videos on the New Parents section of our website (cdss.ca/parents). You can also include things like:

"We are unsure of what the future holds but right now we are just enjoying this beautiful baby."

"Down syndrome is just a small part of our baby."

You might get mixed responses from your friends and family. Many will be in shock and will grieve the same way you did. Some people do not have a good understanding of Down syndrome, therefore they may see Down syndrome as a sad and negative thing. One way you can help educate your family and close friends is by referring them to the New Parents section of our website, sharing this book with them, or sharing the online book *Your Loved One is Having a Baby with Down Syndrome* (downsyndromepregnancy.org).

Many of your close friends and family will want to support you. Invite them to learn along with you. It is important to tell your friends and family about the joy of having a new child, and all the positive things that people with Down syndrome can accomplish and learn. Remind them that you are learning with them and you may not have all the answers to their questions. It's also okay to be honest about the worries that you have and your uncertainty of what the future will hold.

Telling others can help you create a good support network. It will also help educate others about having a baby with Down syndrome and all the things they add to a family.



"Celebrate your beautiful, new baby; your joy will make you irresistible and draw others closer to learn and love."

– ELIZABETH POPOWICH

Everything Is Going To Be All Right

BY PARESH MISTRY



I remember as if it was yesterday. We were at the pharmacy and had just told the pharmacist that our precious baby girl, only three weeks old at the time, was born with Down syndrome. Then, almost as if on cue, an employee of the pharmacy (whom we had never met or seen before) came running out from the back.

“Sorry, I couldn’t help but overhear about your baby. I just want you to know that my niece has Down syndrome and she brings so much joy to all our lives. You don’t need to worry about a thing; everything is going to be all right,” she said, as she grabbed my wife’s hand.

Those positive and heartfelt words of encouragement are forever etched into my brain. And she was right. Everything is all right.

Jaya, now eight years old, has brought so much joy and love into our lives, just as her two older sisters, Kareena and Sanjana, have. She is a positive, outgoing, friendly, and determined little girl. She gets along with everybody and is actually a bit of a

celebrity at her school because of her outgoing demeanour and her very infectious laugh. We were not prepared for that!

Being a parent is one of the most rewarding experiences I can think of. And like all good things in life, you need to put in some work and effort. Sure there might be a different set of challenges in raising a child with special needs, but every child is different in their own right. That’s what makes life so interesting!

Having a child like Jaya has caused many positive changes in our lives. We got together with six other families and created an amazing support group. We help other families by creating awareness, education, and an opportunity to network every month. It has also helped us to really look for and recognize the capability within all individuals with Down syndrome. The list of positive effects is endless when you really think about it.

However, there are days when life ‘happens.’ We all have good days and bad days. Everyone has to deal with sickness, either ourselves or those around us. It’s very easy to get stressed out over the small things in this day and age. No matter how stressed I get, it all goes away when I get a hug from my little JJ (our nickname for Jaya).

It is in that moment, in that very simple and loving embrace, that I am reminded of the fact that “everything is going to be all right.”



Dr. Skotko and Susan Levine have a free online workshop on his website titled “What Your Other Children Without Down Syndrome are Thinking: Sibling Issues for Parents.”

(brianskotko.com/workshops)

Siblings

After giving birth to a baby with Down syndrome, many parents are worried about how it will affect their other children. This is understandable. The good news is that a study done by Dr. Skotko and his colleagues, found that “an overwhelming majority of parents feel that their children with Down syndrome have a good relationship with their siblings.” He also found that 94% of older siblings to a child with Down syndrome are proud of their brother or sister.

Each of your children will have their own unique journey with their sibling with Down syndrome. Some siblings will take on the role of caregiver. Others may find it difficult to understand why their brother or sister with Down syndrome seems to get extra attention. This may make the sibling feel resentment or embarrassment toward their brother or sister. Some will have questions and concerns for their sibling. Depending on the age of the sibling you may have to share more information with them to help them understand Down syndrome and what makes their brother or sister unique.

Keeping your other children informed about their sibling with a disability can help them feel included and important. Each sibling will handle having a brother or sister with Down syndrome in their own way. As a parent, be there for them and answer their questions the best you can. Allow them to have time to themselves and with their own friends.

Overall, your children’s relationships will be similar to typical sibling relationships. Many siblings even say that their brother or sister with Down syndrome is the best thing that ever happened to them.

Some recommended books:

We’ll Paint the Octopus Red
By Stephanie Stuve-Bodeen (for young children)

Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters
By Brian Skotko & Susan P. Levine (for older children)

My Brothers

BY JOHN FLEWELLING

My name is John Flewelling. I am 19 years old and very proud to have two brothers with Down syndrome and two brothers without.

One of the most frequently asked questions that I get is “What is it like growing up with brothers with Down syndrome?” The answer I always give is that it has never felt any different than growing up with my other brothers. Other than some learning and behavioural issues, I’ve never felt that I’ve had to treat them differently or limit myself or my brothers because of their disability.

When I first learned my brother Patrick (now fifteen years old) had Down syndrome, I initially felt confused as to what it was and what this meant for my life. What would people think? Do I have to act differently or treat him differently? These questions were quickly cleared away and I realized that it didn’t matter what other people thought about my brother because he is my brother.

When I learned that my youngest brother Joseph (now ten years old) was on the way and that he would also have Down syndrome, I knew that it wouldn’t matter and that I would love him for who he is.

Although my brothers are younger than me, I have friends who have older siblings with disabilities and their feelings are the same. At the end of the day, this person is their sibling and they are going to love them no matter what. They are able to bond as a family, and are not being treated differently due to their disability. They are able to learn from each other and in turn learn more about themselves.

My brothers are some of the most inspirational people I have in my life today. They teach me daily about the joys of life, how to care, how to love, and how to be a positive figure to those around me.



“It’s Not Going to Be Easy for Corrine.”

BY CORRINE GRIEVE

I was just 19 months old when my baby brother was born. It was September 27, 1989, and I was so excited! As the firstborn, a new sibling was a very welcome arrival. Little did I know, my mom sat in another room heartbroken; Shawn was born with Down syndrome.

At the time, we were living in Germany on a Canadian Forces Base. That meant no information in English, no other parents to speak with, and of course no Google. The only resource that my parents had was back in Canada, my mom’s mother. Many phone calls took place over that time and my grandma made countless trips to the local library to photocopy any information she could get her hands on about Down syndrome. Then she’d mail it to my mom and dad back in Germany.

My dad knew that Shawn just needed a family to love and support him, so he did just that as my mom worked through her grief. A few years ago I found a letter she had written home. “We have no idea what the future has in store for us,” she wrote. “It’s not going to be easy for Corrine.”

Well, it’s been 26 years since that time, and wow have things ever changed! Shawn is an integral part of our family, bringing so many laughs along the way, like finding him dancing shirtless in my purple pyjama pants Christmas morning just a few years ago. My mom was able to move past her grief and embrace the beautiful little baby in front of her. She and my dad raised a true gentleman, who we love so much. He now has a job, lives with supportive roommates, and truly has a great life.

When I was in university, a professor asked our class what we’d like to do after graduating. I raised my hand and said I wanted to work for the Canadian Down Syndrome Society. I’m proud to say that I just passed my fourth anniversary of working here!

My journey in the Down syndrome community feels so full circle right now. Since starting at CDSS, I have wanted to update the New Parent Package. I am so happy that you are holding it in your hands right now. Knowing how important it would have been to my parents 26 years ago, I want to ensure that this package brings love to those who receive it, that it can help them feel a bit better knowing they are not alone in those dark moments.

So, as I write this, I am putting together the final pieces of the updated New Parent Package. I feel honoured to be part of your journey. My wish is that this package gives you some great hope for the future. I want to be able to tell you that yes, you may not have any idea what the future has in store, but for me, being Shawn’s sister was easy. Having a brother with Down syndrome made me who I am today, in the best way.



Life With My Sister

BY MISCHA HAYEK

In 1969, when I was nine years old and my younger brother Nicholas was seven, Sascha was born. Growing up with two older brothers, Sassy (as we call her) didn't learn how to put on makeup or how to wear dresses. Instead, she learned how to wrestle and how to throw a football. By the time she was 21 and despite being only 4'8", she could throw a Nerf football almost 20 yards with a perfect spiral.

However, Sascha was not born healthy; she had a congenital heart defect. Her breathing was rapid and shallow, and she grew much more slowly than other children. She had pneumonia twice before she was six. I remember my mother cupping her hands and patting Sassy hard around the back to loosen the phlegm in her lungs.

Just before she turned seven, Sassy had open heart surgery and two holes in her heart were closed and a pacemaker inserted. She began to grow quickly and within a few years I could no longer carry her around like I used to.

Growing up, Sascha needed lots of monitoring especially when we rented summer cottages near a lake. But as time went on, Sascha matured and began to entertain herself and didn't need constant monitoring. She began to take on tasks, such as carrying groceries, folding her clothes, and making her bed. She learned how to work the television and stereo. She went to school, learned how to tell the time,

and learned the alphabet even though she never learned to read. She became an expert on dogs and can now identify over 100 breeds. And she developed a cheeky little sense of humour. Sassy will take a cold can of pop and slowly touch you on the arm to see your reaction, or she will wait for you to be distracted so she can steal the last piece of bacon from your breakfast plate. One thing is for sure, Sascha is always keeping us on our toes.



Sascha grew up to be generous and caring too. After our mother died and my father grew too frail to walk by himself, Sascha would bring him water and medicines. She would help him get out of his chair when he couldn't do it by himself, or bring him the telephone. My little sister had become a caregiver herself!

Of course, growing up wasn't perfect. We fought. My parents fought. As individual members of the family, sometimes we didn't get along. But Sascha was the glue that held our family together. We saw much more of each other than we would have without her. I don't ever remember being left out or deprived of anything because of Sascha—my brother and I always got what we needed. All of our relationships were closer and stronger because of Sascha.



When my brother got married and had children, he would take Sascha along with his family on many outings. I arranged my career to be in Ottawa so I could visit the family home often. Before I moved home permanently when my mother died, I would visit several times a week to take Sascha out to movies or for coffee or to throw a football. My brother and I did these things not out of obligation but because we love her.

Sascha has had a good life at 46 years old. She has travelled to Australia with my parents more than 20 times and with me several times to the Caribbean. She takes singing lessons, goes daily to a variety club where she goes for walks, listens to music, and plays games. She loves going to the library, drinking tea, seeing movies, and especially going to the spa to have a massage or to have her nails done. And she's a chatterbox who talks to everyone. She is also loved by almost everyone she meets. Just as any sibling, she can still be exasperating at times. Sascha does things her own way and in her own time. But she's a great person.

People have said to me that Sascha is lucky to have had brothers like Nick and I. But I don't see it that way. I believe that we have been the lucky ones. Sascha has been a gift, and that's how I think of her.

*“All of our relationships
were closer and stronger
because of Sascha.”*

Emmanuel & Joel



Joel is ~~A~~ Cool!
I Love him
he is the
Coolest one ever



Max & Libby

Max and Libby can be seen in the short film "I Love Grilled Cheese," which is in the New Parents section of our [website](#).

Family

Having a child with Down syndrome will affect everyone in your family: parents, siblings, grandparents, and extended family. Everyone processes information differently; allow time for every family member to adjust. By supporting family members in learning and understanding Down syndrome, you will help them learn about your new family member and all the possibilities that the future holds for them. Together you and your family can support each other. Share this book with them to allow them to learn with you.

Concentrate on your entire family and not solely on one child. Although a child with a disability often needs more attention for healthcare needs and advocacy, it is important to view a family as a team and see that everyone has a role in helping to support a family member with a disability. Spend time with your other children so they are reassured that they are still important and valued in the family.

Your child needs you to be healthy, so be sure to take care of yourself. There are many ways to reduce the stress that can be associated with raising a family—choose something that works for you. Take time for yourself when you can, allow friends or family members to help when they offer, and ask for support when you need it. Your child will need you to support them through any health challenges and to be involved in their therapy and early intervention programs. Taking care of yourself will ensure you are able to support them.



“The joy your child will bring will be just like the joy that any child brings to a family.”

– ANONYMOUS PARENT

Long Distance Love

BY STAN & JAN MANSELL

We appreciate the opportunity to share our thoughts, observations, and experiences about our granddaughter Kirra, who was born in Australia four years ago.

We were thankful when we learned about “a problem” with her health that her parents, Wendy and Michael, had decided to give this precious life a chance to survive and would do everything they could to help her develop to her full potential.

We were anxious and shocked when we learned that she had a heart condition, but were reassured by the experiences of others and in the books our daughter Wendy sent us to read and learn from. Because we were living in Canada, we were thankful Michael’s parents were there to support them and learn everything they could about Down syndrome and the challenges that faced them as a family.

There were medical procedures we didn’t know much about, or understand, but the family had full confidence in the doctors to know what they were doing.

All we could do was pray for the baby’s healing, and strength and courage for the parents as they stayed by her and willed her survival, and loved her through it all.

We quickly realized God was teaching us about His unfailing love, compassion, and acceptance of these young lives.

Kirra has been a wonder and joy to see as she was half a world away for the first two years. We were so excited to find out the family was going to move to Canada. She has been a pleasure to love and hold since she has been here.

It’s such a blessing to see Kirra develop her skills and be such an energetic, curious, ever-learning little girl, beautiful in every aspect of her development.

We see Kirra about every two weeks, and in these past two years, we have seen the progress she is making. She especially responds to those who make her laugh, and she is a joy to watch at these times. She also has a lovely smile of appreciation for what others do for her.

We have seen, via Internet, and read about her other journeys and adventures. We know that consistent work, patience, and love of her family and educators will carry her through the challenges and opportunities of life.

To our daughter and son-in-law, we appreciate all the work and effort you have put into Kirra getting the right care and educational opportunities. We are proud and appreciative of both of you.



This Much!

BY GRAMMA JOAN KOLBAUER

Receiving a call on Christmas Eve morning in 1998 that our first grandchild had been born was really the best news my husband and I could have received. The call came from California, where our daughter, Laura, and her husband Peter, live.

Zoë Elizabeth Gregor's arrival was two weeks early. I wondered how I could wait two more weeks for my vacation and scheduled flight south. Two days passed and then came the call I could never have anticipated. "Mum, they think Zoë has Down syndrome and has to stay in the hospital for a few more days for tests."

Two weeks later we were at their home and the call came. Zoë did in fact have Down syndrome. By then we were completely in love with this precious baby but had no idea what the future held for her.

Between visits to California, Zoë's parents sent us many VHS tapes which we watched many times to see her progress. We saw and heard her first giggles, rolling over, sitting up by herself, and her excitement when the theme song for Teletubbies came on! Did I mention the hundreds of photos?

Here at home in Winnipeg, I placed a call to the Manitoba Down Syndrome Society, who provided me with an information package typically given out to new parents and was told about "chat nights." They were interesting! The year I retired I had the privilege of attending my first Canadian Down Syndrome Conference held right here in Winnipeg. That was like a shot in the arm for me and an experience I won't soon forget! I have since attended eight national conferences – they are so worthwhile!

I was also blessed with the support of other Canadian parents of children with Down syndrome. This networking has been invaluable!

Zoë was blessed with early intervention, and at three years of age, entered the school system. Once while on vacation there, I was delegated with putting her on the school bus! My goodness, how I agonized over that. She was only three!

As soon as Zoë began speaking, I would ask "How much does grandma love you?" and with arms opened wide, we would both chime "THIS MUCH!" We still do!

In 2004, I was asked to join the Manitoba Down Syndrome Society's Board of Directors. I served as their web person and Treasurer for four years. Since retiring from the Board, I have continued to volunteer for two major MDSS programs.

One of them is called Baby Love, where new parents are invited to an informal gathering to meet each other. I truly believe that it's very important to have the support and experience of other "new" parents. Laura and Peter did not have a local society but eventually met other parents through Special Olympics.

Over the years, I have been in awe of Zoë on many levels—her amazing memory, her love of reading, music and dance, and more importantly her dedication and love for school. She loves her family, friends, pets and activities—golf, ten-pin bowling, dance lessons and swimming to name a few. I am quietly amused by her love of rings—on every finger! Now in grade 11, she continues to love school and the friends she has made there. Zoë attended the 2015 conference with her mother and me, and in her words, "had a blast."

Zoë and I have such a special bond, one I would not trade for the world. How much does our family love her? I have to say, "THIS MUCH!"



What I Wish I Had Known

BY DIANNE SEDORE

Our granddaughter, Ivy, was born on December 9, 2013. My daughter's pregnancy was normal, with no signs of anything out of the ordinary, other than an early ultrasound indicating some calcification around the heart, which can be a soft marker for Down syndrome. However, everything beyond that point indicated that all was as it should be.

We arrived at the hospital to meet Ivy for the first time, with her brother in tow. When I first looked at our granddaughter, I knew she had Down syndrome, although it was not diagnosed at birth. The diagnosis would take another two months to be confirmed. When I look at the first photos of me holding our beautiful new granddaughter what I see in my face is sadness. I tried to keep my thoughts to myself; I held her close and whispered that I loved her and that I would do whatever I could to protect her. I was sad and afraid. Afraid of how the world might treat her. Would she be happy? Would she be healthy? What would caring for her mean to our daughter and son-in-law and extended family?

What I wish I had known...

- *I wish I had known about all the supports available to families facing a diagnosis of Down syndrome.*
- *I wish I had known that the happy moments would far outnumber the moments of worry.*
- *I wish I had known how much our lives would be enriched by Ivy.*
- *I wish I had known that many children diagnosed with Down syndrome are completely healthy.*

But what I really wish is that the sadness and fear had not robbed me of those first few moments when I held my granddaughter.

Be informed. There is so much information available through the Canadian Down Syndrome Society, and their affiliates across the country. Participate in all the wonderful events available to families such as playgroups, family picnics, Go21 events, just to name a few. Children with Down syndrome are as different in their personalities as every other child, they all have different interests and skills.

So to all you grandparents, enjoy every single moment, do not let fear rob you of any of your memories.



Breastfeeding Your Baby

The early days of breastfeeding are a time for you and your baby to get to know each other and learn to breastfeed effectively. Every nursing mother must make some adjustments during this time because every baby is unique. As you get acquainted with your baby, you will discover that babies with Down syndrome have physical characteristics that may have an impact on breastfeeding. While you probably will not encounter all of the challenges discussed here, understanding your baby's particular needs will help you to get breastfeeding off to a good start. In some cases, you may need to advocate for yourself and your baby to get the support you need. Babies with Down syndrome can and do breastfeed, but it may take time and patience. We hope that these tips help you and your baby have a successful breastfeeding experience. However, you may need further support or your baby may not breastfeed at all. Find the way that works best for you and your baby.

BENEFITS OF BREASTFEEDING

Breastfeeding a baby with Down syndrome is not only possible, but provides important benefits to both mother and child.

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

POSITIONING

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

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

LATCHING ON



Express some milk onto your nipple prior to breastfeeding, this may encourage your baby to latch on. Also ensure your baby gets a large mouthful of breast tissue, this will help your baby draw the milk out and stimulate the breasts to produce more. To do so, hold your baby in a comfortable position and use your free hand to support your breast in the C-hold (thumb on top, fingers underneath) well behind the areola, the pigmented area around your nipple. Tickle your baby's lips

lightly with the nipple and wait for them to open their mouth very wide, then pull them in close to your breast with the nipple pointing up into their mouth. If it doesn't quite work the first time, be patient and try again.

SIGNS OF EFFECTIVE BREASTFEEDING

Perhaps the most obvious sign of effective breastfeeding is adequate weight gain in your baby. This should not be solely relied on, however, as babies with Down syndrome often gain weight at a slower rate than traditional milestones suggest. You cannot actually see the milk going into your baby, but here are things you can check for to ensure your baby is nursing effectively:

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

Typically, it takes one to two minutes of your baby on the breast before let down occurs. During this time, your baby will suck rapidly, pausing after every 3 or 4 sucks to swallow and breathe. After the let down, sucking becomes slower and longer with a pause between most sucks. Listen for sounds of swallowing coming from your baby, approximately two to three seconds apart. Swallowing noises may be subtle and difficult to hear. You may find it helpful to have a partner or professional listen with a close ear the first few times you breastfeed. You can also try placing a finger lightly under your baby's chin—you should feel a delicate, repetitive movement as they swallow.

Potential Influences

HOLDS

As babies with Down syndrome often have low muscle tone, including reduced muscle strength in their tongue and lips, good head support is particularly important for your baby during breastfeeding.

There are a variety of ways you can hold your baby while breastfeeding to support their head, neck, and upper back. Applying gentle, steady support to the base of your baby's head will help them to suck well without tiring. However, it is important not to put too much pressure on the back of your baby's head, as it can cause a poor latch.

Some different ways to hold your baby are:

Cross-Cradle Hold

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

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



Football Hold

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

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

To feed from the left breast, hold your baby's torso under your left armpit and use your left hand to position their head onto your left breast. You will find it helpful to support your baby with a pillow at your side to ensure you and your baby are most comfortable. Applying gentle, steady support to the base of your baby's head will help them to suck effectively without tiring; you should be supporting the upper back area and neck, keeping your baby's head steady with your fingers below their ears.



POSITIONS

Dancer Hand Position

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

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



Other Positions To Improve Milk Flow

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

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

SLEEPINESS

Many babies with Down syndrome are very sleepy the first few weeks after birth, which can hinder their feeding routine. To establish your milk supply and ensure your baby gets enough milk, it may be necessary to wake them to feed every two hours, or at least 8-12 times a day. It may also be challenging to keep your baby awake for the duration of the feeding. The hind milk, obtained in the latter part of the feeding, is higher in fat and calories which are important for growth. It is important that your baby receive these nutrients.

There are a variety of tips you may use to keep your baby awake during breastfeeding:

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

Your baby can be encouraged to continue active suckling, and get more milk, by using breast compression and/or switch nursing. These are described on page 41.

TONGUE THRUST

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

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

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



Weight Gain & Supplementing

Babies with Down syndrome are typically born underweight, so it is important that they are monitored for weight gain. If you are breastfeeding, ensure your baby is actually receiving and swallowing milk from you. If your baby is not gaining weight, seek advice from your doctor. Four ounces a week is considered adequate weight gain, but it is not unusual for a baby with Down syndrome to gain slowly even when he or she is receiving enough nourishment. If they are not being given anything but your milk, a baby who is getting enough to eat should have six really wet diapers (more if using cloth diapers) and three to five bowel movements a day (beginning after the fourth day). An older baby may have bowel movements less frequently, but they should be plentiful.

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

It is better to avoid giving supplements in a bottle until your baby has been breastfeeding well for three to four weeks. While they are learning how to breastfeed, exposure to artificial nipples and a different type of milk flow may cause nipple confusion, since sucking at the breast is different from sucking on a bottle.

If you choose to offer your milk as a supplement, there are a variety of methods for you to choose from. If your baby can latch and needs supplements of either expressed human milk or formula, you can use a nursing supplementer or other methods that avoid artificial nipples. The nursing supplementer is a small soft tube that rests on the breast like an outer milk duct. This method is helpful because the baby suckles at the breast while receiving the extra flow of milk from the small tube.

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

During the time that your baby is learning to breastfeed effectively, you may need to offer supplements after most feedings. Some babies nurse better if they get some of the supplement before they are put to the breast, rather than waiting until they are upset with hunger. One size does not fit all; your family physician or lactation consultant will be able to offer you guidance on what techniques will work for you and your baby.

OTHER STRATEGIES

Breast compression is done when your baby is breastfeeding but sleepy or not actively sucking. Use one hand to squeeze the breast firmly but not so hard that it hurts. Your baby should start to swallow. Keep squeezing until your baby stops or slows down their sucking again. When you release the pressure, your baby will increase swallowing; once it slows down, squeeze again. Repeat the squeezing and releasing until it no longer works, and then offer your baby the other breast.

To try switch nursing, watch for your baby to lose interest in active suckling, then slip a finger in the corner of their mouth to break the suction and offer the other breast; your baby should nurse more vigorously. When their sucking slows again, switch him back. Keep repeating this until they seem satisfied. You can combine breast compression and switch nursing or do just one or the other. You will see what works best for your baby.



A Special Bond

BY SONJA MALANIUK

On a sunny day in June my husband David and I sat together on the edge of the hospital bed in shock and disbelief. The doctor had told us that our tiny daughter Ana Rose, born mere hours earlier, had Down syndrome. It was a complication-free pregnancy with Ana. I had undergone a Caesarean section similar to the birth of my son—how could this be?

Our ecstasy quickly turned to heartache and worry: What is Down syndrome? Will Ana die? What did we do wrong? A thousand questions pierced my brain. The most prominent being: Where will we go from here?

Prior to Ana's birth, I had breastfed our first son, Alexandar, with no difficulty or setbacks. I enjoyed breastfeeding my son; this was an opportunity for us to bond. In addition, the nutrients breast milk provided kept his immune system healthy and strong. I had planned on sharing this same experience with Ana and I wasn't going to let Down syndrome stop us.

The hospital staff told us that babies with Down syndrome just didn't breastfeed. Much to their dismay, David and I were persistent. Ana was connected to a feeding tube in the Intensive Care Unit, but we continued to travel to and from the hospital every few hours, night and day, in an attempt to feed Ana naturally. Regrettably she showed no interest in the breast. Day after day we introduced her to the breast and time and time again, she refused to latch on. I sadly watched as the milk dribbled down her cheeks. I felt hopeless.

After three days, David and I began to comprehend the fact that Ana might not breastfeed. We decided to feed Ana breast milk through a bottle, which we considered the next best thing. Unfortunately, Ana refused the bottle as well. I was devastated.

In the wee hours of day four of Ana's life, a nurse who had been supportive of our breastfeeding efforts all along, called to inform us that Ana was once again awake to feed. David and I got dressed and trekked over to the hospital under the night sky. I sat down in the ICU and thought I might as well try breastfeeding Ana one last time. As per usual, she declined the first breast I offered her. The nurse came over and showed me an alternative way to hold Ana. Much to my surprise, Ana opened her mouth wide and latched onto my breast. Could this really be happening? Yes it is! Just when we were ready to give up, Ana latched on. I was amazed! Tears ran down my cheek as my husband and I watched our baby girl breastfeed for the next twenty minutes.

Since that night in the ICU, our breastfeeding journey has had its highs and lows. Some days Ana latches on with ease, other days she refuses the breast altogether. It has taken a lot of time and patience, but now, at eight months old, Ana is latching on consistently.

Breast milk has greatly impacted Ana's development. Because of the nutrients it provides, Ana has already reached many of the developmental milestones for her age and she is a relatively healthy baby. The physical contact of breastfeeding has created a special bond between my daughter and me. Ana's tongue is stronger and protrudes less; I attribute this to breastfeeding, as well. It has been a long and sometimes difficult journey, but I am glad my husband and I stuck to it. I encourage other mothers to persist on the journey of breastfeeding, yet recognize that not all babies will breastfeed. Regardless of whether your baby is breastfed or bottle fed, remember that the most important thing you can feed your baby is love.



Ana at 1 year

“Regardless of whether your baby is breastfed or bottle fed, remember that the most important thing you can feed your baby is love.”

A New Experience

BY JULIA FLUMERFELT

My daughter, Bethany Kathleen, who has Down syndrome, is our third child and our only girl. I had thoroughly enjoyed my breastfeeding experience with both of her older brothers, Joshua and Joseph. I had received a lot of help and good advice from the local chapter of La Leche League, worldwide proponents of breastfeeding. One of the bits of information I remember hearing from these experienced moms was that a baby who became accustomed to the flow of a bottle could have a lot of difficulty learning to breastfeed.

They did not know Bethany!

Bethany, born with Tetralogy of Fallot, a malformation of the heart, found it very difficult to nurse. Her muscle tone was very low. Even before my let-down reflex had kicked in, she would have worn herself out and fallen asleep. She was soon losing weight at an alarming rate. The nurses at the small rural hospital where Bethany was born were very frustrated and became quite short-tempered with me when I told them, time after time, that Bethany had not fed. One nurse even grabbed my breast and tried to force it into my daughter's tiny mouth! I protested, insisting that I was experienced at breastfeeding and that it was my child who needed further medical help.

Thankfully our doctor acted promptly, sending Bethany and me to the Children's Hospital in a larger centre nearby. In the neonatal intensive care unit, Bethany was immediately given several feedings by gavage or nasal tube. Her weight loss was arrested within 24 hours. In ten days, Bethany was ready to come home.

All this time I had been providing milk for Bethany with the help of a mechanical breast-pump that definitely had me identifying closely with the dairy cows of our home community! When we left the hospital, I was given a hand-operated "hydraulic-action" pump, which worked very efficiently. I developed very muscular arms!

For two months I pumped and Bethany fed from a bottle. Rather than focusing my energy on the reality that my daughter could not breastfeed, I concentrated my efforts on ensuring Bethany was receiving the nutrients of breast milk, one way or another. A lot of milk ran out of her mouth when she bottle fed, and she never really seemed to be enjoying her meals. She ate a lot though, and I began to fear she might outstrip my ability to pump enough milk for her.

When Bethany was two months old, we took her and all her bottles and breast-pumping paraphernalia to visit friends out of town. One afternoon we arrived ahead of our friends at their home. The doors were all locked, and Bethany's equipment was inside! She became a little fussy, so I decided to offer her my breast just for the comfort of it. Much to my surprise, she latched on at once and nursed strongly, without the slightest dribbling!



Bethany never took a bottle again. She loved every minute of nursing and snuggling and rocking with me—so did I! I weaned her directly onto a cup shortly after her first birthday. I credit her relatively "healthy" first year to her being able to have my milk. Though her heart defect could not be repaired until she was three years old, and she remained very small, Bethany developed with few respiratory problems and no incidents of heart failure.

Support For Breastfeeding

All babies benefit from breastfeeding or receiving breast milk. Sometimes, information, support, and encouragement are all that is needed to get over the challenge; sometimes, practical interventions are required. Other times, breastfeeding just doesn't work out. Lactation Consultants can assist with supplemental nursing devices and pumps. Your health nurse or doctor can provide information on other feeding options.

For further support and information, La Leche League Canada (LLLC) is available for assistance. LLLC has both meetings and volunteer Leaders. Leaders operate more than 160 LLLC Groups in communities across the country. Each group holds monthly meetings where accredited leaders facilitate informal, guided discussions. During these discussions mothers receive accurate, up-to-date, and personalized breastfeeding information and support for their role as a breastfeeding parent. In addition, mothers are able to draw on the experience of other mothers who attend.

Talking to other mothers with up-to-date information about breastfeeding and basic infant needs helps to give mothers confidence. Correct information—even before her baby is born—can help a mother avoid common problems. La Leche League meetings provide a friendly place and an opportunity to share experiences.

A wide variety of books, leaflets, DVDs and other resources of interest to parents are available through LLLC.

LLLC Leaders also offer email and telephone help to nursing and pregnant women who seek breastfeeding information. To find the La Leche League Canada Group in your area, contact us online or in your local community. You can also call the **La Leche League Canada Breastfeeding Referral Service at: 1-800-665-4324.**



LA LECHE LEAGUE CANADA

Website: LLLC.ca

Phone: 613-774-4900

Early Intervention

Babies with Down syndrome are expected to meet all milestones; however, they are often met at a slightly slower rate. Below is a chart that suggests when milestones will be met. Many children benefit from early intervention to help them reach their milestones.

MILESTONE	RANGE FOR CHILDREN WITH DOWN SYNDROME	TYPICAL RANGE
Gross Motor		
Sits alone	6 – 30 months	5 – 9 months
Crawls	8 – 22 months	6 – 12 months
Stands	1 – 3.25 years	8 – 17 months
Walks alone	1 – 4 years	9 – 18 months
Language		
First word	1 – 4 years	1 – 3 years
Two-word phrases	2 – 7.5 years	15 – 32 months
Personal/Social		
Responsive smile	1.5 – 5 months	1 – 3 months
Finger feeds	10 – 24 months	7 – 14 months
Drinks from cup unassisted	12 – 32 months	9 – 17 months
Uses spoon	13 – 39 months	12 – 20 months
Bowel control	2 – 7 years	16 – 42 months
Dresses self unassisted	3.5 – 8.5 years	3.25 – 5 years

From National Down Syndrome Society - www.ndss.org



“Love your baby, accept the fact that you have a baby with special needs. We are sweet, loving, and caring. When your baby grows up, support them and teach them to be their own advocate one day.”

– DEWLYN LOBO
(CDSS Board member)



Early intervention refers to programs that are available for children from birth through to about five years old. These programs provide children with disabilities the necessary supports for them to start working on skills that will be beneficial in their development. There are many different early intervention strategies. Common early intervention programs for children with Down syndrome are physical therapy (PT), speech-language pathology (SLP), and occupational therapy (OT).

In early intervention, professionals will observe your child’s gross and fine motor abilities, language skills, social development and self-help skills, and will then develop a program specific to your child. This will allow for your child’s individual skills to be developed and strengthened. Early intervention is important for children with Down syndrome.

Starting early intervention programs as quickly as possible will have a positive outcome for your child. Development and learning begin right away.

Depending on which province you live in, assistance for services can differ. Contact local Down syndrome organizations and provincial/federal offices about the services available in your area.

Your child could be introduced to many specialists and therapists during their first few years. If you feel that something is being missed, don’t be afraid to talk to other professionals or parents to make sure your child is receiving all the support they need. They may be able to suggest additional therapies or programs that could benefit your child. It is important that you advocate on behalf of your child, as you know your child best.



“I Love You, Too!”

BY SCOTT ANDERSON

Hello. I'm Scott.

I have been blessed beyond measure, and here are just a few reasons why:

- I've been married to Denise, the girl of my dreams, for over 18 years.
- We've journeyed to China to adopt Libby, an amazing girl who is almost 6 (and acting as if she's 16).
- We have a son, Max (just 2.5 months older than his sister), who introduced us to the amazing world of Down syndrome.

Writing an article like this—being transparent and vulnerable—can be difficult. But sometimes you have to be open and honest, and realize that your stories, experiences, shortcomings, failures, successes, victories, insights, and hindsight may help other parents feel they are not alone.

So what have I learned so far?

- I am now an expert in raising kids. Two kids to be exact. (Just our two kids. Please don't ask me how to raise yours.)
- Being a parent is easy. Parenting is harder, and parenting well takes considerably more effort. It's work. Exhausting work. But highly rewarding.
- Typically-developing children (like Libby) seem to practically raise themselves, while Max challenges me every day to be intentional in how I parent both my children.

When Max was 4, I had a doctor ask us why we didn't have prenatal testing, clearly indicating we didn't need to have a child with special needs if we'd been tested. Wow. I didn't feel any anger, but I did feel sadness. Because here was a medical “professional” who was lacking some basic information.

And for every person like him, I've run into a hundred others who see exactly what I see: a child whose value in this world is immeasurable.

For example, Max has the seemingly rare gift of empathy. Somehow Max knows when someone needs a hug. He'll simply walk right up and give them one. I can't recall how many people I've heard say, “I really needed that.”

I know some people, if they had the opportunity, would love to have their child's disability taken away.

Not so with me and my Max.

I can't explain it, but there's something about Down syndrome that makes him... for lack of a better word... special.

- He lives to laugh.
- He becomes upset when he feels he's let me down.
- He'd stay on a playground swing all day long, if I let him.
- He doesn't care who's watching when he's dancing to a favourite song.
- He loves pancakes, cupcakes, and Fridays (grilled cheese & movie night) more than anyone.
- He says, “I love you, too,” before you even get a chance to say it first.
- He's the real deal.

And he makes me want to be a better person. I often wish I could be a lot more like Max.

I still have so much to learn from my son, and I can't wait to see what the future has in store for us.



*“He makes me
want to be a
better person.”*

Life At The Whyte House

BY DIANE WHYTE

Like people—families come in many different shapes, sizes, personalities, and with challenges. We started our family 26 years ago in Montréal, when our first child Kyle was born with Down syndrome—along with a huge smile, big appetite, and strong muscle tone. He did not fit the mould for the “normal” child. We quickly learned that he was creating his own mould.

We never thought much about how we would bring up our children. We thought we would go with the flow and it would happen naturally. After all, I was one of four kids and my husband one of three, and we turned out just fine.



Others always told us that we were special parents; that Kyle was lucky to have us. However, we did not feel “special.” Instead, we felt jealous, envious, sad, and angry that we had to deal with so many more issues than other parents did. It was not fair! We felt that it was going to be a long and bumpy journey.

The book *Babies with Down Syndrome* was our first source of information. We learned that Kyle is a child FIRST and has Down syndrome second. We attended our first CDSS conference in Toronto, and were overwhelmed with the realization of all the possible things that Kyle could accomplish. We knew then that we had lots to do, but we felt better; we had hope. He was surrounded by our extended family who helped us create an environment of love. He attended an inclusive daycare where he would learn from his peers, and at the same time, he taught them about acceptance.

We moved to Ontario and immediately got involved with a local parent group. It was the best thing we could have done. We connected with other families who have children with Down syndrome (who remain our life-long

friends) to compare notes, look for guidance, help with milestones, and listen when we needed to vent. We started working with Occupational Therapists, Physical Therapists, Speech-Language Pathologists, and Music Therapists.

Now, Kyle attends day programs and various activities and sports which keep him busy and active. Luckily he has been in good health and is regularly checked by an ear, nose, and throat doctor, his family doctor, dentist, optometrist, etc. He still has a huge appetite, and a big smile across his face when he asks for something special!

Like every family, Kyle’s two sisters (now 24 and 19) endured their share of sibling rivalry, jealousy, and pressure to feel responsible for him. But there was also love, support, and fun. They also claim he gives the best big brother bear hugs!

Back then, when Kyle was born, resources were very limited. Now, we can easily access any website, download learning videos, and receive New Parent Packages like this one. Awareness campaigns through the media, billboards, and popular culture are making it easier for people with Down syndrome to be accepted. However, with so much information out there I always tell new parents to trust their own gut. It is easy to listen to other people, but you will know what is right for your child. After all, they take their lead from you. Remember to celebrate every milestone along your journey. I truly believe “it takes a village to raise a child”—any child!



Proud To Be Her Dad

BY CAM SCHIMKE

Dear New Parents,

Congratulations on the birth of your child!

I'll never forget the day my daughter Blair was born. It was a crazy Sunday with my wife being induced 5½ weeks early, a long three-day labour, and at the end our beautiful daughter coming into this world. We were prepared to be in the NICU, but not for our pediatrician coming into the recovery room and telling us our new baby had signs of Down syndrome. I spent that night lost and full of emotions. Even though I didn't know much about Down syndrome, I knew that we had a beautiful, healthy little girl that needed her dad to be strong for her.



When Blair's diagnosis was confirmed four days later we were surprised at how it was delivered. We were told to grieve the loss of the child we thought we were going to have. While I was scared, I have never ever felt like we were unlucky to have Blair in our lives. No parent should feel this way. My wife and I made a deal to stay away from Google and to not read about all the scary things that could happen. I think it's important to remember that you are a new family and you should be celebrating bringing something amazing into this world, not grieving it.

Again, congratulations!

There will be challenges, particularly that first year, but every parent faces these and we all get through them. Telling your family and friends your child has Down syndrome is hard, but I found that the positive support and congratulations you will get for becoming a father make you realize your child's diagnosis doesn't have to be and shouldn't be something that defines him or her.

When we came home from the hospital, I realized I wanted to reach out for help to learn more about Down syndrome, but living in a smaller city like Red Deer made it harder to find resources. It wasn't until Blair had heart surgery at the Stollery Children's Hospital that I found the Edmonton Down Syndrome Society and reached out to them. From there we started going to play groups, events like Go21 and the Canadian Down Syndrome Conference, and seeing a pediatrician at the Edmonton Down Syndrome Pediatric Clinic. Blair goes to early learning classes with

peers her age who also have Down syndrome. Finding these supports have helped us find a community to help us through our journey. When you're ready, I would encourage you to do the same.

It's important to remember you have a wonderful addition to your family. Being a dad to Blair is so much fun and the older she gets the more fun we have together. She is her own unique individual and I can't imagine my life without her. Blair's diagnosis didn't stop us from growing our family like we had planned and she is a wonderful big sister to her baby brother Ethan who was born 18 months after her. In the beginning I felt lost and alone but once you feel ready, I recommend you reach out to all the great resources and people that are out there. No matter what, Blair is my sassy little girl who always brings a smile to my face and I am thankful for her each day.

– Blair's Dad

Promising Futures

Although you may be overwhelmed with all of this information, the future is very bright for people with Down syndrome. Now more than ever there are great supports and programs that allow people with Down syndrome to flourish.

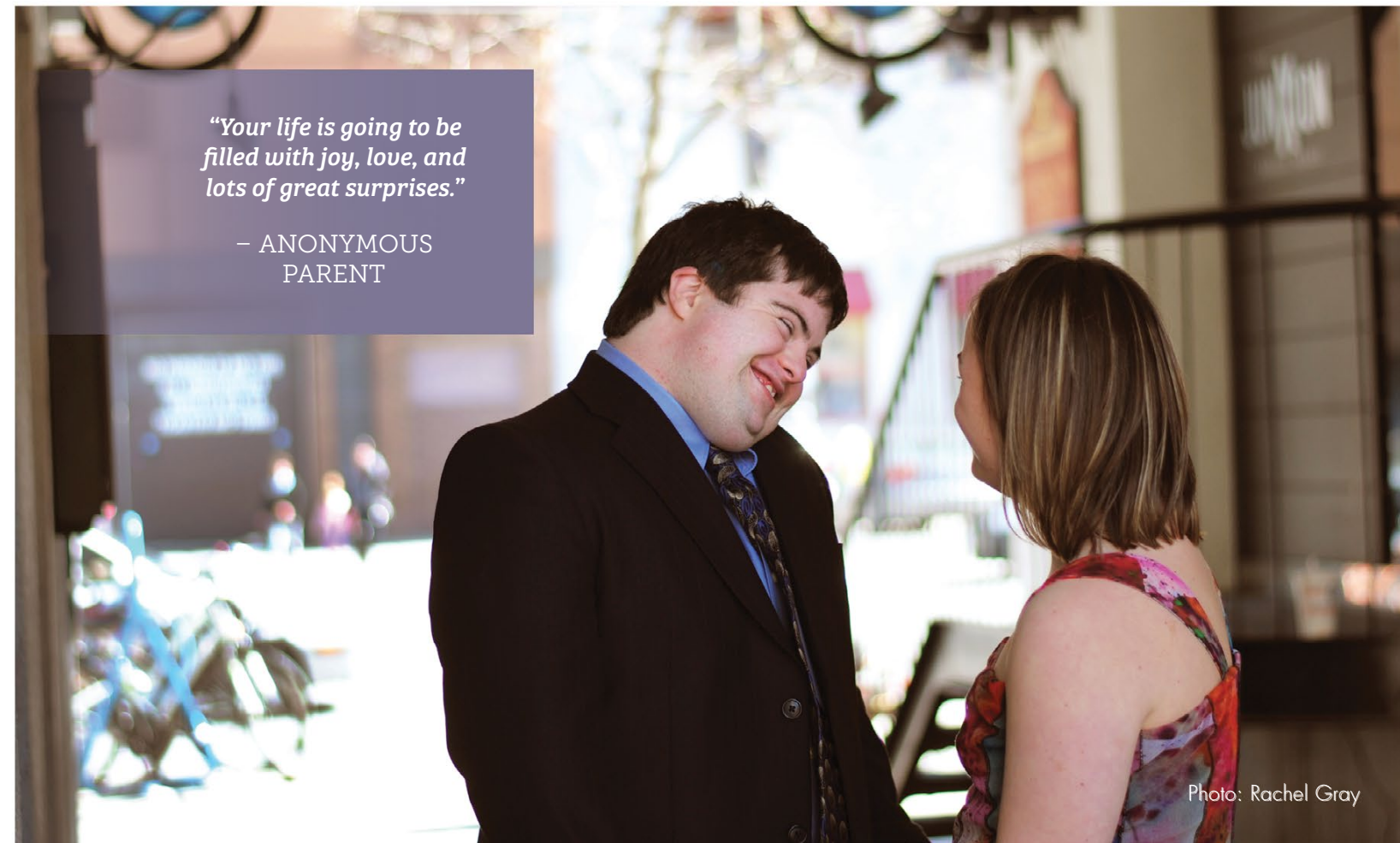
People with Down syndrome are living longer, happier, fulfilled lives. This can be attributed to the positive shift in the inclusion of people with Down syndrome in school and community, early intervention, and the development of accessible resources. Many people with Down syndrome attend post-secondary school, get jobs, and are choosing to get married.

Raising a child with Down syndrome will be much like raising any child. There will be ups and downs, challenges and successes, smiles, laughs, and tears. We would love for you to share all of that with us! Connect with us through email or social media!



"Your life is going to be filled with joy, love, and lots of great surprises."

– ANONYMOUS PARENT



Next Steps...

Taking care of you and your baby is the most important thing in the first few months. Give yourself time to adjust and enjoy the pleasures of having a newborn. Most importantly, just like any baby, your baby with Down syndrome needs love. As you adjust to your newborn, there are resources that may help you on your journey. Some of these include local groups, internet communities, and books.

LOCAL GROUPS

When you are ready, connecting with a local Down syndrome group near you can be a great starting place after welcoming your new baby. Many towns, cities, and provinces have organizations, meet-ups, and support groups to connect local families. A list of local groups can be found on our website. Take a look to see if there is one in your area.

CDSS and participating local groups offer a New Parent Visiting Program in many locations across Canada. This program allows existing parents of children with Down syndrome to visit with new parents. These parents are able to share local resources and personal experiences with you. You can find participating local groups that have a New Parent Visiting Program on our website.

ONLINE

Many new parents find it helpful to connect with parents who have been in their shoes. If you aren't quite ready to be a part of your local group, many parents are now connecting online.

The Down syndrome community has so many wonderful parents who are willing to share their stories as a way to inspire and uplift other parents. Often Google can be an overwhelming starting point when learning about Down syndrome. Visit the New Parents section of our website to see which blogs we recommend. Below are some websites you may want to visit first.

CDSS.ca: New Parents section

cdss.ca/parents

Our New Parents section has much of the information featured in this book in an easy online format. Some information that is not included in this package is also available, such as a printable health checklist to give your doctor if they do not have experience with Down syndrome.

NDSS.org: New Parent Package

ndss.org

This New Parent Package is offered by the National Down Syndrome Society, an American organization.

Down Syndrome Pregnancy

downsyndromepregnancy.org

This website has an assortment of excellent books available for download.



BOOKS

Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives

If you don't already have a copy of this book, we highly recommend you get it. Mothers share how their lives have changed since having a baby with Down syndrome. We have heard from many that this was their favourite book to read after their child was born.

Down Syndrome Parenting 101: Must-Have Advice for Making Your Life Easier

Author Natalie Hale shares her best advice for parents, grandparents, and teachers who have someone in their life with Down syndrome. Natalie, an international speaker, is also a parent to a son with Down syndrome.

Babies with Down Syndrome: A New Parents' Guide

This is a great book to have on hand while raising a child with Down syndrome if you need more medical information. Rather than read it cover to cover, have it available in case something comes up that you have questions about. This book covers most health concerns that *could* occur, but in most cases won't. It is not necessary to overwhelm yourself with all of the "what ifs" that may never happen.



FAQ

Are there government programs or services to help my family? When should I apply for them?

Yes, each province and territory has a different way to provide support to families with a child with a disability. You can find a helpful resource on our website under the New Parents section. Another great resource is other parents in your community.

What will life be like growing up with Down syndrome?

Your child will have more opportunities than a child born with Down syndrome even five years ago. People with Down syndrome have shown they can excel in areas never thought possible. There are more supports and resources available to people with Down syndrome now. Children with Down syndrome now have the opportunity to be included in inclusive classrooms with their peers. A lot of work has been done in improving advocacy and acceptance for people with Down syndrome. This has made it possible for people with Down syndrome to get a university education, find employment, and live independently. Your child with Down syndrome will face some challenges in his or her life but with the proper supports and resources your child will be able to live a full, meaningful life.

FAQ continues on page 58.

VATTA

Voices At The Table for Advocacy is a group of adults with Down syndrome that sit on a committee of the Canadian Down Syndrome Society. Members were asked to answer: "What was it like growing up with Down syndrome?" See what they had to say...

To find out more about VATTA, visit cdss.ca/vatta.

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"Growing up with Down syndrome, I just wanted to be included and liked. I wanted to be educated, have a career, have friendships in many communities. Those dreams are coming true!"

— WILL BREWER



"At first, I didn't think I had Down syndrome so I was just a regular guy. Then I realized I have Down syndrome and I'm still a regular guy. I am proud of who I am; proud of my Down syndrome. At first, I kind of wanted to be more like my brother, Lucas, with no Down syndrome. But now, I want to ask a question, "What is normal, anyway?" For a while, I let my Down syndrome disgrace me but now it has made me stronger. I am very proud. I won't ever let it disgrace me again. It made me stronger."

— NICK POWOWICH



"Growing up with Down syndrome is something special. You meet new people and you start to get to know them and that's when a community builds. A community is where you are welcomed and valued as a person, an equal. Growing up with Down syndrome means that you are extra special, it means that it doesn't matter if you have an extra chromosome. It just means that you're special in a way that's different."

— JESSIE HUGGETT

"I believe that it is great to have Down syndrome. I did not always feel that way, but now I know that having Down syndrome is awesome. I think that our extra chromosome is cool. CDSS has helped me 'See the Ability' in everyone, especially in myself."

— BRANDON THIELEN



"I work hard to learn things. I did get some help when I was younger to develop skills. If I ever need help, I can ask for help. Growing up with Down syndrome taught me to not give up when things get hard and to work through it. Things will change if you make it happen for yourself. We can be proud of who we are, and we are important just like everyone else."

— MATTHEW MACNEIL

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"Growing up, I made friends through the Edmonton Down Syndrome Society and through Special Olympics. The friends I made through these activities are still my friends now. If I did not have Down syndrome, I would not have the friends I have today."

— ALANA GERSKY



FAQ Continued...

What materials do you recommend to help me learn more?

Woodbine House publishes excellent books about Down syndrome that we highly recommend. Some other groups have also developed their own new parent information books. You can find more information about these on the New Parents section of our website.

I'm still pregnant. Should I do anything different to prepare for my baby's birth?

Like any expectant mom, you should try to get the rest you need. Allow yourself some time to learn about Down syndrome. Help your family and friends learn about Down syndrome. Any feelings you have are okay. Allow yourself and other people close to you to grieve, but also to celebrate the expected arrival of your baby. You can start to look into early intervention programs in your area and provincial government services. You can also connect with a local group close to you. We also recommend reading *Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome* from downsyndromepregnancy.org.

What if I don't have a Down syndrome clinic in my area or my doctor has no experience?

On the New Parents section of our website, you can find a document that you can take to your doctor. This includes a checklist of health screening that should be completed. You can also talk to other parents. There are many local Facebook groups—find one that's near you.

What are the chances of my next child having Down syndrome?

Your chance of having a second child with Down syndrome is just 1% higher than the typical statistic (americanpregnancy.org).

"I asked my mom how I changed her life. She said that I have introduced her to an inclusive and diverse community. My mom said that I have taught her joy. And also that she now has met lots of great people who she would have never met if it wasn't for me."

— JESSIE HUGGETT



Halton
Down Syndrome
Association
HDSA

Special thanks to the Halton Down Syndrome Association who generously supported the printing of 21 Welcomes.

DR. SKOTKO et al. RESEARCH

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Société canadienne du
syndrome de Down

The Canadian Down Syndrome Society (CDSS) is a national non-profit organization providing information, advocacy, and education about Down syndrome. CDSS supports self-advocates, parents, and families through all stages of life.

OUR MISSION:

To empower Canadians with Down syndrome and their families. We raise awareness and provide information on Down syndrome through the prenatal, early childhood, school years, adulthood, and retirement stages of life.

OUR VISION:

All people are valued, fully participating citizens.

CDSS PROVIDES:

- Up-to-date information through cdss.ca for individuals with Down syndrome, their families, educators, caregivers, and professionals.
- Two free information lines: 1-800-883-5608 and info@cdss.ca.
- A self-advocate-led committee called VATTA (Voices At The Table for Advocacy), which advises CDSS on what is important to the community.
- Publications, including *VOICES* (written by and for people with Down syndrome) and *21 Magazine*.
- Resources like this package, as well as the *Educator Package* and *Mind & Body: Answers To Your Questions* are available in digital and print formats. Where possible, our resources are also available in French.
- 21 Monthly, our e-newsletter, which keeps members and donors up-to-date on what's new in the community and at CDSS.
- A network of over 50 Down syndrome groups in Canada.
- A YouTube channel (youtube.com/cdndownsyndrome) featuring videos about Down syndrome by people with Down syndrome.
- Exclusive resources from CDSS in various fields, supporting all life stages of a person with Down syndrome.

JOIN CDSS:

We work for you! CDSS offers memberships for self-advocates (adults with Down syndrome), families, individuals, and organizations. CDSS works to get YOUR voice heard. Visit cdss.ca to join.



See the ability