WOULDN'T
CHANGE
A THING

WE ARE FAMILY

A collection of short stories from families who Wouldn't Change A Thing.

For many families when they first get news of Down syndrome, immediate questions begin with: "How will this affect our other children?" "How will this affect our family?" "Will this negatively impact our relationship?" and many many more.

To coincide with our 2021 World Down Syndrome Day campaign we wanted our families to have a voice and share their stories so that new families might read them when they have those questions.

Throughout this eBook, there will be many stories from all kinds of families. Siblings' voices, cousins, aunties and uncles, parents, blended families, single parent families, same sex families and more. We hope these stories bring reassurance to families who have recently had news of Down syndrome. Reassurance from those families living with an extra chromosome, their voices can only give the true lived experience perspective.

A Sibling Story

Esther and Iris, siblings (written by Becky Clark)

Alongside being excited about our second pregnancy, I felt a fair level of anxiety. At times I lay awake at night, worrying that we were doing a disservice to our then 18-month-old, Esther, who has Down syndrome. "Would we be able to give her enough? Would we be able to give her sibling enough? Would she feel ousted by not being the baby anymore, would her sibling feel put out by the extra support Esther needs? What would their relationship look like?" All relevant, I think, but compounded by the hormones and insomnia that pregnancy can bring. It seems to me that everything feels worse at 2am.

The reality for us is that it's all fine. Better than fine, it is wonderful. Esther is our firstborn child, she is nearly 4, she loves running, jumping, climbing, music, Moana, Singing Hands, playing with dollies and singing Happy Birthday to us all multiple times a day. She is a proud big sister, and she loves going to preschool. She is determined, a problem solver and always looks a little bit like she's been dragged through a hedge backwards. Iris is nearing 2, she is funny, headstrong and independent. She loves Hey Duggee, teddies, having tea parties, jumping in puddles and finding sticks outside. She has a cheeky smile and is currently rocking a Boris Johnson style hairdo.

Although their development is nearing a similar level, Esther is still very much a big sister, and she takes pride in the role. From the moment we brought Iris home, and our usually boisterous toddler gently stroked her head and shushed her, to more recently when she guided her sister in on her first day of nursery, clearly proud to show her what's what, she has taken her responsibility seriously and it is sweet to watch. Evidently, she spends a substantial amount of time at nursery 'popping' to the baby room to check up on Iris and occasionally leading her astray. Every morning Esther marches downstairs and opens the door with a huge grin and 'Hello, Iris' (one of her first 2 word phrases) to get her up. When Iris goes down the slide in the park, her sister is at the bottom giving her a big, enthusiastic cheer. When Iris falls over, or gets upset, Esther is there to offer a cuddle and a reassuring stroke of the arm.

Iris looks up to her sister - she is her number one fan, following her lead. She copies everything Esther does. They are co-conspirators, they have a look they give each other when they're about to do something cheeky - egging each other on (this usually involves climbing on my kitchen table or breaking into the snack cupboard). They also bicker, over dollies and toys mostly, I often feel like I'm a referee!

As sisters they have given each other someone to compete with, someone to show off to, someone to care for and have fun with. I have no doubt some of Esther's motivation to complete more challenging tasks is to show her sister. I think the same goes the other way too. At the moment, it feels a bit like we have twins on developmental level, but things are changing quickly. There are points at which I see Iris overtake her sister, mastering skills that took Esther months within a few days. Her speech has come on and is currently similar to Esther's level, I imagine it will only be months until it is better than Esther's.

I know this will change their dynamic and no doubt there will be challenges down the road. Sometimes I worry about what they will be, and I am acutely aware that this sibling relationship may in many ways look different to the one we had imagined, but if and when challenges come, we will accept and deal with them. For now, we're doing our best to make them each feel valued and loved for who they are and are enjoying watching their bond.

A Sibling Story

By Harvey aged 8, brother to Cian 2

Hi, my name is Harvey, I am 8 and from Kent. My little brother is Cian, who is 2 years old and he has Down syndrome. I am going to tell you what it is like to have Cian as a brother....

Me and Cian have lots of fun together, we enjoy playing, laughing, singing and watching TV. I don't like it when Cian goes into my room and plays with my toys. Cian is very funny; we always have lots of laughs. And sometimes when I'm reading Cian will copy me and pretend to read too. He also steals the book when I am reading which is very annoying!!

During lockdown, I have not been able to see my friends. This means that Cian and I have played lots together. In the summer we went in the garden and I pushed him in the baby car. Cian can walk now so he wants to play outside with me all the time.

We watch Mr. Tumble so that Cian will learn Makaton. I have been teaching Cian lots of signs and songs to help him to learn and understand. I love Cian very much, and he is the best baby brother I have ever had all of my life.

Cian had some operations, and I was a bit sad when Mum and Cian were in hospital, but 2 weeks later everyone came home, and we were a family together again. I was overjoyed to see all my family come home and we had the best night ever.

Cian has Down syndrome which means it takes longer for him to learn, that's why we all learn Makaton. Cian will be going to my school soon which I am very excited about. I will show my friends and introduce Cian to all my friends.

A Sibling Story

By Emily 7, sister to Alice 4

Hi I'm Emily and I'm 7. I'm a big sister to a terror tot called Alice. She's my little sister and is lots of fun (sometimes!). In my family there is Mummy, Daddy, me and Alice. We have 2 Nanna's and 1 Granddad. Alice looks cute but sometimes makes me mad, but then she signs sorry and gives me cuddles and kisses. We love doing crazy dancing with very loud music, Alice is great at head banging! Alice has just started at my school and my whole school learnt to sign "You've got a friend in me" to welcome her.

My friends love Alice and think she's famous! Me and Alice love playing outside, going on walks and on our bikes. Alice is always ready to play, even when we are meant to be asleep! When we go shopping, she says hello to everyone, if they don't say hello back, she says it louder until they do!

She makes me smile and giggle all the time, even if I'm supposed to be being told off! I wouldn't change a thing about Alice, she is the best little sister.

A Sibling Story

My Brother Archie by Zachary aged 11

I was three years old when my little brother was born, so I didn't really understand when my Mum and Dad explained that he had Down syndrome. Now however, at the age of ten, I know how my dearest brother will change my life in the most magnificent ways.

On the other hand, it is inevitable that he will face many challenges alongside my sister and I. A brilliant example of this, is the fact that recently he has had many visits to the hospital, this is because he will soon have an operation to help improve his hearing and his speech, and yet no matter how much his family worries, he always stays strong.

There are many reasons I love my brother, so many that I would probably need one million pages to write them all down, and probably ten million hearts to love him as much as I do. One of the things that he adores me with is his breath-taking smile.

My brother is as funny as anything, he has made me laugh more times than I can count! When he makes me giggle, I can't look him in the eyes for hours, or else I'd burst out with laughter.

Taking everything into account, I wouldn't change a thing about Archie. Yes, he does struggle with certain things, but as long as I share those struggles with him, well, I can accept that.

Zachary.

A Stepdads Perspective

Adam, stepdad to Maizy Moo

So, I met Maizy's mum in 2012, after a few dates she decided to inform me that her daughter, Maizy had Down syndrome. I'll let you into a little secret everyone, I already knew, by the power of Facebook stalking. So, it didn't come as some great shock and why should it, I'm fairly chilled and just accept everyone for who they are. I got to meet Maizy about 4 months in, I was nervous to meet Maizy not because of preconceptions of Down syndrome but because if she didn't like me then it was game over for me and Charlotte.

Luckily Maizy is a right little super, kind, friendly chatterbox so we made friends pretty quick (just to tick one misconception off - people with Down syndrome aren't always happy, they can be right moody little… you know the word). I then spent the next 18 months falling in love with this little person. We would sing together, go to the park, eat brownies in Costa and just be friends. I loved taking her to primary school to drop her off because she had loads of genuine friends there.

One quick good point about Maizy is she talks nonstop, so the bonus to that is I can never fall asleep at the wheel on long car journeys. I'm not going to lie, there are some small challenges when the hormones come along, you imagine having those hormones but not the understanding why you feel so angry and emotional, as your comprehension isn't quite there yet.

She will pick holes in her clothes if they irritate her and she will shout at me if I'm tapping the steering wheel in the car. Maizy now has a little brother, who loves to annoy her. He normally does this by pretending he's horrid Henry and she's Margaret. He will ambush her while she's halfway through practicing her audition for X Factor dancing and singing to little mix. Maizy has an even younger sister who loves Maizy to bits and Maizy just loves having a sister. She always wanted a sister, that's what she wanted when her brother was in Charlotte's tummy. Life is full and loud and full of love.

Maybe some people think there will be some stigma with having a child with Down syndrome and that it will have a negative effect on siblings. That couldn't be further from the truth. Maizy is a very, very loved big sister. The hardest part about being Maizy's stepdad is that I'm a stepdad and that's it really.

Maizy is 14 now so I get the same back chat, you're not my dad as any other stepdad would. But that's a problem that any stepdad has, I get told to get out of her room and that I'm not cool now. All I'll say about Down syndrome is it's like bungee jumping, some people will do it some won't. But how do you know if you like anything if you haven't taken the time to talk to someone different and find out about them? But look at it this way, I wasn't given Maizy, I chose to be with her.

If I was going star rate Maizy, she gets 4 and half stars, she would have got 5 but she told me I'm not getting a card for Valentine's Day, so she loses half a star for that.

A Sibling Story

By Brooklyn 8, sister to Bella 6

My name is Brooklyn, I am 8 and I have two sisters. My older sister Charleigh is 24 and my younger sister is Bella, she is 6.

Bella was born with Down Syndrome. Bella is no different than me. She can be really annoying at times, very grumpy when she wants her own way. She likes to sleep in, but I like to get up early. We love to play shop, we love to play on the trampoline, we love the park and just like Peppa Pig we love jumping in muddy puddles.

Bella is in my school and is very popular with all the kids. The teachers all love her too. Our favourite food is pizza and cake. I think that's my mum's favourite as well.

The only thing that I would like to do together is ride our bikes but Bella can't ride hers, so I don't really get to go out on my bike. We get to go out with other families who also have children with Down syndrome, so we have lots of fun and I get to be a big sister to them too.

My friend would love to be me.

My mum asked if I could change anything about Bella what would I change? I said I wouldn't change a thing! Bella is perfect just the way she is.

Brooklyn aged 8

An Auntie's Perspective

Auntie Sarah to Poppie

Our family journey started almost 8 years ago, when after a long time of trying and many years of heartache, my beautiful sister was blessed with a miracle. Throughout her pregnancy we all had our fingers and toes crossed that this time would be the one. With each passing week, our hope turned to excitement…. until finally, after what felt like years of holding our breath, the day came.

It was the 12th February 2013 and like any other day, I was up early and ready for a day of work, but it turned out to be no regular day. This was the day we received an extra special gift…my gorgeous niece Poppie. It was a very emotional day and one we never thought would happen. I remember feeling exceptionally proud of my big sister for her strength during the years she had yearned for a child while watching us all have our own families and overwhelmed with love now, she was able to experience motherhood herself. The day passed in a blur of excitement at being able to meet my new niece, I couldn't wait to visit and give her a squeeze.

On 13th February; doctors discovered Poppie had complete AVSD and they suspected that she may have Down syndrome. Blood test results confirmed their suspicions and a day or two later, the diagnosis was given. It came as a shock; we weren't expecting it but Poppie was loved before she was even born, and her diagnosis made no difference to the love we felt for her or gave her. I did, however, fear the unknown. At the time I knew very little about Down syndrome, that lack of experience and knowledge was what scared me. I had many unanswered questions at the time but as soon as I held my niece for the first time and looked down at her beautiful face, I knew that she was going to touch so many lives and bring joy to our family in ways we didn't know were possible.

At 16 weeks old, Poppie had open heart surgery, she was discharged after a week and recovered fairly quickly from the surgery. This was the first time we saw how strong Poppie was going to be. Her determination soon became apparent to us when she started lifting her head to look at us and responding to the sound of our voices. That was when we knew that Pops was going to do whatever she put her mind to.

There have been many times throughout these past eight years that Pops has shown us how strong, resilient and determined she is…. from rolling over, walking, dancing and singing to the times she's been unwell and in hospital. Every accomplishment, whether small or big; Poppie does it by her extraordinary will power, each milestone or new thing she learns she has pushed herself until she has achieved what she set out to do. Giving up is not an option for our little whirlwind of a niece, she takes every step in her stride and shows us every day that persistence pays off.

Poppie has formed so many beautiful relationships so far, especially with her cousins. My girls absolutely love spending time with Pops. The bond they have is priceless and the time they spend together is full of lots of fun, laughter and many cuddles and kisses. I often refer to them as the Three Musketeers when they are together…. where one goes, the other two follow and they are always looking out for each other.

Watching and being a part of Poppie's life has been and continues to be amazing. The love and pride I have for Poppie is so strong that at times it overwhelms me. Seeing how she has blossomed into the young lady she is today has taught me some valuable life lessons, proven to me that anything is possible and showed me what it is to love unselfishly. Our relationship is precious and is one that will last a lifetime. I honestly wouldn't change a thing.

A Sibling Story

Hannah 26, sister to Grace 10

I was sixteen when I found out that I was finally getting the sibling that my mum and I had dreamed of for years. We soon found out that it was going to be a baby girl but that she had some health issues - that really frightened me. At 34 weeks pregnant, we found our baby girl was going to have Down syndrome. Call it teenage naivety or maybe a feeling of what was to come, but I was genuinely not at all worried or concerned by her diagnosis. While the adults in my life came to terms with the news, I felt peace about our girl's extra chromosome and I just couldn't wait to meet her.

At 36 weeks pregnant, I got the text from my mum that her waters had broken - my sister was on her way! We had decided early on that I was going to be one of my mum's birth partners and I felt so lucky that I would get to see my sister come into the world. I will never forget the moment Grace Isabella was born. The labour room was full of people, anticipating her health conditions, but for a few moments it felt like it was just me, my mum, my stepdad and this beautiful little bundle… my sister.

Seeing Grace grow up has truly been one of my greatest joys. She is such a funny, sassy girl and everyone who meets her comes away slightly changed. She has made me slow down and find more patience. She has helped me to celebrate 'little' milestones just as much as the bigger ones. Her extra chromosome doesn't change our sister bond: I've cried with her as she's stroked my hair and told me it'll be OK, we laugh and dance together, she rolls her eyes and asks when I'm going home when I've annoyed her and we both moan to each other when our mum is in a mood. She is the little sister I always dreamed of and so, so much more.

All the milestones in my life have been made even more special by experiencing them with Grace. One of my first thoughts when I found out that I was going to become a mum myself was how excited Grace would be. I could not wait to experience raising children alongside her. Grace was 7 when she became ‘Aunty Grace’ to Halley and she was a fully-fledged aunty when her nephew Spencer was born two years later. I had so many dreams about Grace with my children when I was pregnant - I couldn’t wait to see them playing in my mum’s garden, getting into trouble together, having dance parties (which is mine and Grace’s favourite thing to do). My dreams did not even come close to the happiness I feel when I see my baby sister in her ‘Aunty Grace’ role. She is, hands-down, my children’s favourite person in the world. Halley loves anything that her Aunty Grace loves because she idolises her so much. And the trouble they get into together… well that is on another level! We’ve had faces completely coloured in with felt-tip, shampoo lathered into my mum’s bed, barricades made to keep baby Spencer out and the thing is, I know that this is just the beginnings of their escapades together. Before long it’ll be stealing my makeup and sneaking out to go to the pub together and truthfully, I can’t wait to see what they get up to.

I feel so lucky, every day, that Grace came along. She healed holes in our family that we didn’t even know were there. My mum and I became closer than I thought was possible when Grace was born - my mum and her mum became closer - she became the glue that held us all.

I’ve heard of parents/expectant parents worrying about the burden that a sibling with a disability brings. I have never, and will never, see my sister as a burden. I love her more than anything, she brings so much joy to my life and I will protect and advocate for her for my whole life. Love is not a burden.

I wish I could go back to my sixteen-year-old self and tell her, you were right, that extra chromosome doesn’t change a thing. Grace goes to mainstream school and loves it, she’s got a big group of friends, she goes to dance class and does modelling all over the UK. And most importantly, she is the most amazing, loving sister and my life is all the richer for having her in it.

God Sibling Perspectives

17-year-old Matt is very privileged to have 4 God brothers and 9 God sisters. He also has 2 biological sisters, Hannah and Rachael. We are one big extended family, and love spending time together.

Jemima, 20 and Deborah, 18

Matt's personality has always brightened up the room, with his contagious energy. He has taught us that body language is the core of communication, in a world where speech is most commonly utilised. We have never met anyone with such a cheeky, yet beautiful laugh, and someone who can be the light in a room when it's dim.

Matt's warm and welcoming hugs are not the only amazing part about him! His great intelligence is something that can never be overlooked. He is a person who knows what he wants and does not struggle with indecisiveness when it comes to his wants! We love him for that!

He teaches us that emotions should not be disregarded or set aside - and can be expressed in various ways, to your loved ones. Matt has taught us, and many of those who love him, a great amount - always wear a smile first before anything else.

Teifion, 25

"I have known Matt since birth, and it is the first time I have really experienced having someone close to me who has Down syndrome. I have learnt so much, about both Matt as a person and DS in general, from the very first day I met him, that I can't really imagine what my life would be like if I didn't know him.

Although Matt has had a long period where he doesn't use sign that much to communicate, initially it was used all the time and I had the experience of growing up with him and learning signs from his parents, at the same time he was learning them. So, although I am nowhere near fluent, that has had a lasting impression on me and I'm glad to see that he is using sign again more and more.

One of my first substantial memories is going on holiday to Switzerland with Matt's whole family. As both of our parents are friends, they spent a lot of time with each other and, in turn, so did we during the holiday. Some of this time would just be Matt and I slightly isolated away from others, and so I got to see first-hand how he reacted to new sights and experiences which, all in all, helped me in being able to see the world through someone else's eyes. Also, as there was no verbal communication, I learnt to use the other senses in order to communicate, such as watching Matt's reaction when he tries a new bit of food or when we put something on the TV. This has been important in my general life, as well, as it helps me empathise or show compassion with others, and to read things such as body language and expressions, instead of just relying on what someone says - which isn't always necessarily the same as what they're thinking or how they're feeling.

Matt is an amazing friend, and, with all his quirks and traits, I will never meet another person like him. Although living with someone who has DS is different and, maybe, something some people never experience, I wouldn't change anything for the world! I'm glad I met him at such a young age, as it has had a positive effect on my general outlook. I've learnt so much that I probably never would have learnt or experienced, had he not been in my life."

Cerys, 23

"Matt-Cat is my God brother. I was very young when he was born, and he first came to our house when he was about 1 week old. So, I have experienced nearly 18 years of Matt. I have learnt to be more compassionate to other people's needs, from having Matt in my life. It's been interesting to learn how to communicate with someone who doesn't talk but, for example, if he wants a hand tickle his actions always make it very clear. I have enjoyed getting to know him and getting to know how he asks for what he wants/needs. I remember when Matt would run up to strangers

for a hug - he is such a friendly boy and he just wanted to share love with everyone. He has always had such an infectious smile and is such a loving person, which its why it's been so easy for him to teach me how to treat everyone with the respect and compassion they deserve"

Asante, 17

"Having known Matt for half of my life, and not once having a full conversation with him doesn't change the fact that I have so much love for him. His personality really does shine through. He has such a bubbly and funny character, and never once fails to give off that positive energy to the people around him. Matt having DS and autism doesn't change anything! Even though it's not the same verbal relationship I share with my God sisters, I wouldn't change anything about him. I just hope he knows how much love I have for him, as he never fails to put a smile on my face even if my day is not going to plan. Over the years I have witnessed Matt's growth and I am really proud of him for the young man he is today. I am honoured to have Matt as a God brother. Matt is family and that's all that matters."

Chelsea, 16

"Having a God brother with Down syndrome has been fun! And kind of educational! And I wouldn't change anything about him. Due to living with Matt, for a while, when I was very young, I see him as my brother, and I love him in that way. Being with him on a daily basis helped me understand and adjust to his disability. Before that, I had never really been around anyone with a disability before. Matt not being able to speak, and me never being able to have a full conversation with him made it harder to communicate with him. However, it wasn't a huge problem to me, as he still understood me, and I learnt to understand him. As time went by, it became a lot easier as I got used to it, and he uses sign language a lot more frequently now.

Having a God brother like Matt means that you become more educated and knowledgeable for the future. Also, you are able jump queues and get good parking spaces which is a huge bonus when we go out on family trips! The fun days out have been an honour to go to, as they are very enjoyable and you meet a lot of other people like Matt which I loved. Matt is very cheeky! He never fails to make anyone around him smile. Every time I see him, he makes me laugh! He is very loveable and is always up for a huge cuddle. I love him for who he is and who he is becoming. Being there, and watching him become a man, and much more independent, is so amazing to see. I am so proud of him, and am grateful to have him in my life."

Brian, 20

"Having known Matt for the majority of his life, I have watched him grow and develop so much through the years. Before meeting Matt, I don't think I had heard of Down syndrome or autism. However, I quickly realised that though Matt was different, he also wasn't!

Matt is a lovable, funny boy, who lights up any room he enters.

Although Matt cannot speak, I, and others, have always been able to communicate with him well. We have learnt Makaton sign language, which is what Matt mainly uses to communicate. Learning this has benefitted me, and also enabled me to understand Matt's feelings and get closer to him. It also helps me to communicate with others, in the future, who I may meet with Down syndrome or a learning disability. As he becomes older, it's amazing to see how independent Matt is becoming, and "manly" too.

Meeting Matt and being part of his life has had a great effect on me, and I've cherished every moment."

Big Brother Story

"Down syndrome, what do you see? I see Jude and Max looking at me."

I was six years old when my little brother, Jude, was born. At the time of his birth, I did not know anything about Down syndrome. My dad found some videos from ESPN that showed individuals with Down syndrome doing cool things in sports. He showed these videos to my sister and I to try to help us understand a little bit about Down syndrome and to show us that Jude would be able to do awesome things as he grows up. My parents also taught me about the different characteristics of individuals with Down syndrome.

One day, my mom picked me up from my kindergarten class. As soon as I got in the car, I was so excited to let her know about my friend with Down syndrome. My mom was confused, and she asked if there was a new student because she knew that nobody in my class had Down syndrome. I explained to her that I knew he had Down syndrome because he had little ears low on his head. My mom quickly explained that my friend did not have Down syndrome, and she asked me if I had mentioned anything to my friend. I answered her, "Yes, I told him that he had Down syndrome, and that he was like my little brother, Jude." My mom explained to me that I could not go around telling people that they had Down syndrome; only doctors could do that. I asked her why, and then I told her that there is nothing wrong with having Down syndrome. She assured me that I was right; there is nothing wrong with having Down syndrome, but it still needs to be left up to the doctors.

Growing up with Jude and Max hasn't always been easy, but it sure has been fun. By the way, Max is my other little brother that my family adopted from China; he has Down syndrome as well. When I was younger, I was into Hot Wheels and Nerf guns. Max and Jude are also into those toys now, so it has been great playing with them.

I have started to introduce them to sports like fishing, baseball and basketball. They have definitely enjoyed playing baseball in the yard and dribbling the basketball.

My dream for them is not only to be able to play sports but to be the best at them and show people that even though they have Down syndrome, it does not mean they cannot do amazing things. When I found out that Chris Nikic completed an Ironman competition, it really showed me what individuals with Down syndrome are capable of achieving in their lives.

The boys and I also really enjoy jumping and wrestling on our trampoline. We sometimes play a game that we call, “Down, Set, Hut,” where you say those words and then try to tackle each other.

Playing with the boys has truly made me a better person and has taught me how to be more patient. I hope people look at Max and Jude and think that they are cool dudes who love to play and wrestle instead of a person who has less value or incapable of doing things.

I love Jude and Max so much that I work hard every day to be a good role model for both of them. Max and Jude bring so much joy and pure love to my family. I am so blessed to be their big brother!

Twins Parent Story

Suzanna Mum to Theo and Bella

Our journey has been a very emotional one. When I first found out I was pregnant with twins I was so excited, and it wasn't long before they asked if I wanted the test for DS. I knew straight away I didn't want the test for DS as it made no difference to me whether my babies had DS or not, it wouldn't change how much I want or love them. Then one day they noticed something on a scan that meant there may be a problem with one of the twins. Possible duodenal atresia. They then wanted Theo monitored more. I was then upped to 2 scans a week as the blood flow through Theo's umbilical cord had slowed down and had so much fluid in his sac, they had to drain 1 litre of fluid from my stomach. Because they were already taking the fluid and kept saying everything's adding up to Theo having DS, I agreed to them testing the fluid. I just wanted to know so I could prepare. The test came back positive, yes it was very emotional as no one expects it, but it didn't make me any less excited, I couldn't wait to meet him.

He then started struggling a bit more but because I was having twins the decision whether to have them early was a lot tougher than if it was just him. I found out the survival rate for a baby with DS making it to term was 50%, so I was terrified. I was 34 weeks and I had to make the decision as to whether I had them early to save him and risk his twin Bella having medical issues from being early or hold on to give her a better chance and risk losing him. It was a no brainer. I was not losing either of them.

The next hurdle was they needed to deliver them but due to Theo possibly needing an operation on his bowel when he was born, he couldn't be born at my local hospital. So they had to find a hospital that had two beds available at a Surgical Neonatal unit. I live in Cornwall and the closest hospital with beds was Cardiff. So, my partner and I had to drive the 4hr journey to Cardiff to have our babies.

Both babies were healthy but needed support as they were so early. Theo needed more than his sister Bella. They scanned his bowel ASAP to see what they needed to do. It turned out his stomach and bowel were not connected so at 4 days old weighing 2lb 7oz, Theo had major surgery to join them together. That was the longest 6 hours of my life waiting and not knowing how he is. Theo is a fighter and conquered every battle he has had to face. Bella was in hospital for 5 weeks; Theo was in hospital for 7 weeks. Luckily, I could get free accommodation for their whole stay, they were in 3 hospitals in total to get us closer to home and I was with them every day for the full 7 weeks.

When we came home, I was so happy and really couldn't believe it, it felt like a dream. They are now 21 months old now and even though I see the big differences in Bella and Theo's abilities and development, they are both changing so much every day. I love having twins and they are both so amazing, so happy and chilled out. Theo is so relaxed, not much seems to faze him. They constantly make us smile every day and their faces light up when they smile.

I've joined the local DSA support group and it's been amazing, meeting other people with children with DS and hearing all the positives rather than focusing on what he can't do, I've learnt to get excited about what he can do.

I can see the bond between Bella and Theo growing more and more every day. She tries helping him as much as she can. Bella is running and climbing over everything and Theo is still trying to learn to crawl and stand. If Bella sees me trying to do Theo's physio, she always tries helping him and holding him. Theo still just takes bottles as he won't take solids and Bella tries holding his bottle for him. Theo is always watching Bella and trying to get to her, and it makes my heart want to explode when I see how much they love each other.

Yes, it was a scary start and such an emotional time, but I always knew I wanted to be a mum, it's all I ever wanted, and I feel like the luckiest woman in the world. I can't wait to see what the future holds.

A Sibling Story

My little brother Thomas, by Daniel Aged 13

My mum has been a childminder all my life, so I was used to having babies in our house, what I really wanted was a baby of our own. When I was 4 my mum and dad told me that mum was pregnant, and we were having a baby!

I was so excited, I remember watching mum's tummy grow and feeling our baby kick, then mum told me I was having a baby brother, I was even more excited, I imagined all the fun I would have with my baby brother and all the games we would play.

I have always loved playing football and couldn't wait to teach my brother how to play it too.

I helped dad to paint his room and I helped my mum sort through all the baby clothes. Then came the day that my brother was born. I came home from school and dad told me mum was already in hospital and I would be staying overnight at our friend's house.

I remember my dad calling to say that Thomas had been born, but that he would need to stay in hospital for a while so the Drs and nurses could help him get better.

The first time I saw Thomas, I was so excited to see him, we walked into the SCBU my mum was waiting for us. Thomas looked so tiny, he had lots of machines beeping around him, he also had a tube in his nose to help him feed and was on oxygen, so there were lots of wires. But they didn't scare me, I just saw my beautiful baby brother.

I told him who I was, that I loved him very much and when he was bigger, we could play fun games, he squeezed my fingers and looked at me, the nurse then asked if I would like to hold him which I did, so mum sat me in a big chair, the nurse put a big cushion on my knee and then she gave me Thomas so I could cuddle him, I was so happy!

Then mum and dad explained to me that Thomas had been born with a hole in his heart and that he would need to have a large operation when he was bigger, this made me really worried, I remember asking my mum if Thomas would die, and both of us crying, but mum told me Thomas was strong and that the Doctors where very clever and they would fix his heart and help him get better.

When he was five weeks old Thomas came home, I was so happy I was allowed to give him his milk, I helped mum every day to look after him, we went for walks, I cuddled him and sang him songs.

Then when he was nine weeks old, he had a bad cough and his Doctor wanted him to go back to the hospital, this made me feel really sad, I wanted him to be home with us.

I went to visit with dad, as my mum was staying in the hospital with Thomas.

It was really strange not having mum and Thomas in the house again, but I knew the Doctors and Nurses were looking after Thomas and making him feel better. One day dad said that Thomas was being moved to a new hospital and that he was going in an ambulance. I was really jealous that he got to ride in the Ambulance while I had to go in our car.

Dad explained that the special hospital, just for children, was where Thomas would stay until after he had his heart operation, because it was a children's hospital, they organised lots of activities not just for the patients but the siblings too, so it was really fun, they had lots of toys and a big playroom on every ward.

Thomas had a room of his own so mum could sleep there too, the nurse said I could colour pictures which we could hang on the walls, so Thomas knew I was thinking of him, I drew lots of pictures. We went to the hospital every day to see Thomas and I could still cuddle him because the nurses let me lay in his bed with him.

Then he had his heart operation and was on the ICU, this time it was very scary seeing him with so many wires. The Doctor showed me a big monitor with Thomas heartbeat, he said that Thomas' heart was fixed, and he would be able to go home when he was better.

When he was off the ICU and back in the heart unit, we were allowed to have family and friends come to the hospital and visit Thomas. I couldn't wait for him to come home again, the Doctor explained to me, my mum and my dad that Thomas had to have oxygen at home. So, one day a man came to our house with a large van and big tanks of oxygen that we could use in the house, Thomas was also needing a feeding tube, so the nurses showed mum and dad how to use the feeding tube and pump. Then Thomas came home, he had to go back to the hospital for checkups, I was nervous each time he went as I wanted him to come home again afterwards, and he did. He has never needed to stay in hospital overnight again. About 3 months after Thomas came home, his Doctor told us he no longer needed the oxygen at home, that he was better, so I gave the Doctor a hug.

At home I would help mum try to give him food so we could wean him off the NG Tube, his favourite was scrambled eggs and broccoli which I thought was funny, I don't like broccoli so I would give him mine and say I was helping! We had a big party for Thomas' 1st birthday, it was fun having our nana and all our friends there, he was funny and made everyone laugh, I was so proud helping him blow out his candle and watching him eat cake.

During Thomas' first year my mum and dad had mentioned Down syndrome to me, but I didn't really understand it, it also didn't bother me, to me he was just Thomas, my baby brother. As he got older mum and dad mentioned it more, they told me it was due to an extra chromosome, that he may be smaller than other children and that he may be slower to learn than other children, but it was very important to encourage him to learn lots of things.

Thomas is now 8, he is really healthy and active. We have family holidays, we go on trips to the zoo, to the park, walking in the countryside, we go to the cinema and for meals out. He loves to go swimming and can even swim underwater. We do everything that other families do. Thomas having Down syndrome doesn't stop us from living a normal life. At home we play football together, he loves scoring goals and being a goalkeeper. We have lots of fun playing hide and seek and board games. He is really good at building towers and playing with Lego and Playmobil, he has a great imagination and likes to make up games, he also likes to play dress up. I am teaching him how to play on the

PlayStation with me, although he needs a little help, he is learning how to play football games. We have family movie nights, and he helps mum bake cakes.

Thomas likes to play jokes on me and my friends, he knows all their names and loves giving them high fives and playing with us, they all know he has Down syndrome, but to them he is just Thomas, they always accept him for who he is, nobody has ever been mean to me about Thomas. He wants to be involved with everything I do, which is usually fine, and I like playing with him, but it's not always possible. And while usually Thomas is the happiest and smiliest little boy, he can become grumpy and upset, if he isn't allowed to join me, but he calms down quickly too.

He is funny and kind and he gives the best hugs, he is very empathetic and likes to take care of people when they are sick. I was sick last week and Thomas wanted to take my temperature, he sat and stroked my head and sang songs to me, which made me feel happier. He is also very polite and well mannered; he always says please and thank-you and he loves to help people. He is very sweet to all the little children that our mum childminds for, he helps her to feed them and he teaches them colours, numbers and animal noises.

He goes to school and he has lots of friends of his own, he enjoys learning and tries really hard, he is learning to read in Dutch and English and can recognise all his letters and quite a few words. He can speak and understand both English and Dutch, he also really likes learning to sign and can do that in both languages, which I think is pretty amazing.

I don't know what Thomas would have been like if he hadn't been born with Down syndrome. He would have been a totally different child, so it's hard to say. But I don't think it would be too different. I'm so happy he is who he is, from before he was born, I've loved him more than anything and that will never change. He fills our lives with so much love and joy.

He has completed our family in a way nobody expected, his extra chromosome has changed all our lives in such a positive way.

Down syndrome is not something to be scared about or worried about. I wouldn't want him any other way or change a single thing about him.

A Sibling Story

By Jemima aged 13

Overall, having a sister with Down syndrome is pretty cool. Like all things, there are positives and some negatives but overall, I wouldn't change a thing about Pippa.

Pippa is two years older than me so as I was growing up, having a sister with DS was just part of my life. I think when I was younger, I didn't even notice that she was different to other children. For the first two years, it was just us two sisters and so we played together, went to toddler groups together and were really close. I think that's why we are still really close. When I was two and Pippa was four, my brother was born, and I became the middle child – that wasn't so cool!!

Pippa and I began to speak at the same time and so although her speech wasn't always clear to people, I could always understand everything she was saying. I also learned to sign with Pippa by going to a toddler signing class and watching Mr. Tumble, so we have always been able to sign together. Being able to communicate with Pippa has been useful when we've been at classes together because if the teacher doesn't understand what Pippa is trying to say, I can interpret which stops Pippa getting frustrated.

I get on really well with both my siblings, but because Pippa and I were close in age and both girls, we used to do more things together, like ballet classes, joining Rainbows, horse riding lessons and, when we were older, we started theatre school together. We like doing the same things together like dancing, baking, signing and watching Disney films. Pippa enjoys spending time with me and always gives me a hug if she sees that I'm sad. When we are doing things together, as long as I am calm and patient, she will follow my lead and lets me help her with dance moves or cooking techniques; sometimes she is happier with me helping than my mum. When we play family board games, Pippa often chooses to go on a team with me and that makes me feel special. I really like doing things with Pippa and it makes me happy that she is happy and enjoying it.

Pippa is really easy to get along with (easier than my brother!) and having a sister with Down syndrome has never caused me any issues. Yes, some things are a bit different to my friends' families – for example we have to be very calm and quiet during mealtimes because Pippa has difficulties eating and gets very agitated very quickly which can make her sick. We always have to have music on in the car (not the radio but songs Pip knows with no talking or adverts in between) and that can be a bit annoying as sometimes I like to just chat in the car. We also have to stick to quite a firm routine, even when we go on holiday, so that Pippa knows what is happening next and that keeps her calm and happy which makes life easier for everyone! Oh, and we can't be very spontaneous when we are out as we need to take meals and food for Pippa because she has a limited diet. There are some funny things that Pippa insists on – for example when we go to our local zoo (which we all really love) we always have to go to see the animals in the same order otherwise Pippa gets really grumpy and won't keep on walking round!

Having a sister with DS really helps me build my awareness of disabilities and so makes me feel comfortable around people with disabilities. I've also been able to talk to my friends about special needs and so when there are people in school that need extra help, I understand why.

It has also given me lots of opportunities like getting involved with WCAT; learning new skills like signing; meeting new people; going on activity days with charities where I've been able to do kayaking, stand up paddle boarding and boccia; and during lockdown I've been able to do online workshops with Pippa in dancing and singing with another charity. Now I am older, I really like getting involved in raising awareness like my mum does and last year I made a little film about inclusion in Girl-guiding which was really well received. I'd like to do more awareness things in the future.

When I started secondary school it was frustrating because Pippa is really well known there and so for a while I felt a bit like a secondary person, I was always "Pippa's sister" until the teacher's got to know me for myself but now it's quite cool because we get to do things together: at Christmas Pippa sang a solo of Rudolph the Red Nosed Reindeer and the music teacher let me get involved by signing it alongside her which helped give Pippa confidence and gave me the chance to show off my signing!

So yes, having a sibling with Down syndrome does make my life slightly different to other thirteen-year-olds……………… but in a good way 😊.

Big Brother Story

By Tyreese

My name is Tyreese and 3 years ago on the 10th January 2018 my baby brother Darrion was born, along with the unexpected news that he had Down syndrome.

This was a big shock to me and my family, especially my mum since we had no prior knowledge about his condition meaning we were not prepared. This news was very emotional for my family, but we were also grateful to have a healthy baby. My mum was most impacted by finding out about his Down syndrome her mind was all over the place and she couldn't understand how no doctors knew or told her while she was having complications during her pregnancy and scans every other week before his birth while considering the major heart conditions and other traits that came along with it.

I was only 13 when Darrion was born, I've always been caring about people with disabilities but never really aware of those with them in which I see often or through social media. Him now having this disability was a chance for all of my family to learn together and grow in order for us to support him and his needs. Now we know a variety of things about his condition and like to spread awareness and even small facts that most people usually don't know.

The second my brother was born I was eager to meet him and show him off to the world. Down syndrome is what Darrion was born with but it doesn't define him as a person. He's passed barriers that we were told he may not and shown us his true potential in which he continues to do every day. My brother has a smile that

lights up the room without even looking at him. I find it impossible to be mad at him or generally sad when he does something cheeky because I know his smile will peak through and lift my spirits and his hugs fill you with warmth that make you never want to let go. I like to educate people on things they should know about Down syndrome and how much joy they bring into this world while showing off how much progression he is constantly making!

January 10th 2018 was not only the day that Darrion was born with Down syndrome but it was the day me and my family was changed for the better since we now had a bundle of joy and cuteness bringing the family even closer than before. Me and Brendon, our older brother, love Darrion and we always will. We wouldn't change Darrion for the world, but we hope to change the world for him.

Same Sex Parent Adoption

By Kathryn and Gillian, Mums to Kenni.

Kathryn and I have always wanted to adopt. We had been together for over 10 years and married for 4. At the time we applied to adopt we cared for a young adult who was 24 with Down syndrome and her younger brother, 16. We have been caring for them since they were small. We have lots of holidays with them and she loves being part of our family. Tasha was a bridesmaid at our wedding and her brother Charlie walked me down the aisle.

We started our adoption journey in 2017. We attended an LGTBQ information night but really being a same sex couple didn't influence our adoption journey. We enquired about adoption, did a parenting course and were assigned a wonderful social worker who is a great support. We knew we wanted to adopt a child with additional needs as we both have a lot of experience. Having looked after a child with Down syndrome a lot we thought this would be a good match.

We got to meet our daughter Kenni really early in the adoption process. Her social worker was so positive about us meeting her and making an informed decision. We immediately knew we wanted to adopt Kenni and were able to arrange lots of visits to get to know her. Kenni lived with an amazing foster family who we still keep in regular contact with and who love her so much. After her official adoption panel, we took our family to meet her and both Tasha and Charlie fell in love with her. We had a meeting with a medical advisor which was really helpful, but at that time Kenni was keeping very well. When we were due to bring

Kenni home she was ill in hospital and she took two weeks to recover before we could bring her home. At the time it was stressful living in a travel lodge because we just wanted to get her home. Looking back, it gave us an enhanced transition from us and the foster family and allowed us to understand Kenni better before taking her home.

After a month of being at home. Kenni went into hospital for observation and we eventually found out she needed an operation. We spent 18 weeks in hospital due to Kenni picking up lots of viruses. It was a difficult start for us as a family, but the hospital staff were wonderful and celebrated with us when the adoption order came through. Kathryn's mum and dad were able to visit Kenni every day in hospital and she formed a strong bond with them during this time. We got home 2 days before Christmas and we were all exhausted and I had to manage lots of medical equipment, but we were so pleased to be home together.

Since Kenni has come to us we have had a lot of support from lots of friends and family. We have also enjoyed and got great support from the Wouldn't Change a Thing community. We enjoy sharing and reading success stories and seeking advice and support, which we are always grateful for.

Kenni is doing really well and she is a funny, spirited and loving little girl and although our journey has been a roller coaster, we definitely wouldn't change a thing

A Sibling Story

Sisters - Connie 8 and Esme 4

These two may not be sisters genetically, but there is no denying their bond and love for each other.

Despite being four years younger than Connie, Esme shows such compassion and care for her older sister.

Even though Connie has Down syndrome, she has always shown emotional maturity beyond her years and often hugs and comforts her sister.

The care and love Connie showed for Esme from day 1, was far in excess of anything we could have hoped for. We thought it may be hard for her to understand and comprehend how Esme had arrived at our house, but she took it all in her stride: as she does most things.

The girls are so close and often stick up for each other especially if, as Mum, I'm having to have words with one of them!!

Connie says the best thing above having a sister is 'having fun with her': whilst Esme says that Connie is 'her favourite friend and plays games with her and this is what makes her such a fab sister'.

A Sibling Story

By Mum, Charlotte

Emmanuel is 7, born in April 2013 and Amelia is 6 born November 2014 so when I say they are close they really are! I considered myself very fortunate to have a wonderful first pregnancy, with 'bump' often being referred to as a 'textbook baby'.

It was not until the morning after his arrival into the world that dad, Nathan, and I would discover that Emmanuel had to have some further tests and wait for the outcome of a blood test. The consultant came to see us the next day and delivered the news that Emmanuel did have a little something extra - Down syndrome!

Emmanuel was an absolutely beautiful baby and whilst adjusting to this new diagnosis, we loved watching him thrive!

It was a complete surprise when I fell pregnant again. The 12-week scan for Amelia was the day before Emmanuel's 1st Birthday party, only my husband and our parents knew I was expecting again. We threw a big party to celebrate Emmanuel's first year of life and I remember feeling exhausted at the party not announcing the news of our next arrival until a later date.

On 19th November 2014 our second beautiful baby arrived, we didn't know what gender we were having so we were over the moon when we had a little girl as a new addition to our family.

Whilst overwhelmed with excitement and a feeling of completion, I was also really nervous about managing two little children so close in age. Emmanuel had not developed like a typical one year old so in many ways it was like having twins. I needed a rota of friends and family to support me due to me having a C-section and really wouldn't have got through the early months without them! As difficult as it was at times, the bond they had was clear from the start.

The joy of the children being so close in age is that they were inseparable, they did and still do everything together. The same nursery, pre-school and now the same mainstream primary school! They are very close in every sense. Emmanuel is protective of Amelia and Amelia is an advocate for Emmanuel, the bond they share is priceless and they make everyone smile wherever they go! Yes, they fall out, as all siblings do but overall, they are the best of friends.

Emmanuel was 5 years old when his ASD diagnosis was confirmed. Amelia was 5 when she unexpectedly diagnosed with epilepsy - they have both seen each other in hospital and both looked after each other when they have needed to. They both support one another and have the most fun ever together!

It's clear to see that they both mean the world to each other and have a beautiful sibling bond. As young as Amelia is she embraces knowing about her brother's dual diagnosis of Down syndrome and Autism. Amelia just knows Emmanuel is her big brother and she loves him to bits.

Amelia has really helped Emmanuel develop, encouraging him to read with her when he wouldn't have the confidence and he helps encourage her to do new things. It will be wonderful to see them continue to grow and learn together.

A Sibling Story

The Sibling Effect! By Tania, Mum to Henry 7 (DS), Ruby 9 and Monty 6

Quite quickly after having Henry we decided to have another baby. We felt the larger the family the better for our children. For many reasons, fun, companionship, development and support. So, we had another! A little boy called Monty. Monty arrived 17 months after Henry. I had 3 under 3 and the easiest baby of the lot was Henry, he was a dream baby! Ruby was as expected but my little Monty Moo came out screaming like someone was chopping his leg off and didn't stop until he was gone 3.

Ruby was in love with Henry from the minute she met him, always close to him, sat on him A LOT. Even now they have such a special bond, they are next to each other's classes at school and Ruby was so happy when H started. They get on, although still the usual sibling rows and fights but nothing in comparison to the Monty and Ruby combo. It's a beautiful relationship to watch.

Henry and Monty are something else! The best and worst of friends, partners in crime and roomies (their choice)! It's a hard relationship to watch, they fight, they plot, they grass each other up and they have a look where they know exactly what each other are thinking! They are Trouble! (And yes, that is a capital T!)

Both Ruby and Monty have enhanced Henry's life and abilities more than we could ever have dreamed. Ruby got Henry moving, he followed her everywhere with his eyes, then he rolled everywhere after her, crawled, cruised and then walked. Ruby (and food) inspired his every move.

Monty got him talking, at 10 months old Monty was fluent in Makaton, his speech followed quickly with the most impressive vocabulary for his age range (I truly believe Makaton is the reason for this). Henry looked jointly impressed and annoyed that his brother spoke so well, so upped his game, incredible to watch how a child so young can be so determined to be the same.

Henry has enhanced their lives so much too, a brother with limitless enthusiasm, greets them when they come back from the loo like he hasn't seen them for weeks and always up to play or be led astray. A brother they understand needs a little support sometimes and has something a little different about him to other people. A bit like Ruby's bright red hair! Ruby used to think it was called Dancing syndrome, I think that's a fitting alternative personally! He gives the most love, shows the most concern and he'll share anything but food, unless it's Ruby, he'll share anything with Roo.

Not to mention the fact Ruby likes to mention her bro is actually a minor celeb as he starred in the 50 Mum's vid! Massive popularity points at school!

Our children continually mix with children with all different additional needs and don't see any difference or have any thoughts other than friendship. We are well involved in our local Down syndrome group and feel privileged to have met the friends we have through it, all of us. One of the first things that worried us when Henry was born was the impact on Ruby! How silly we thought it would be a negative one.

All in all, the fact they all have each other is special and helpful and just wonderful to see as a parent. So, if anyone is reading this with a new little one with an extra chromosome and you are worried about the siblings, please don't, you have nothing to worry about.

An Aunty’s Perspective

By Chloe about her niece Evie

Evie is our gorgeous niece, an absolute light in our lives. She is our little ray of sunshine and brings such humour and character wherever she is. Evie burst into our lives 3 weeks early, this was much to our devastation as we were on our honeymoon and we missed her birth. Luckily, we were due to come home the next day, after a 9-hour flight, suitcases still piled in the car we went straight from the airport to meet our little niece. We were beyond excited and just couldn’t wait to bundle her up and smother her with love.

It had already been mentioned the possibility of Evie having Down syndrome, but during our visit doctors came to visit her mum and dad to explain. About an hour later, Evie’s dad came to us at the hospital coffee shop, where we had waited. He confirmed Evie had Down syndrome and he indicated for me (Chloe, Evie’s aunty) to go and see Sophie (Evie’s mum). I will never forget walking back into the hospital room and seeing Sophie curled up with Evie in her arms, just stroking her head and staring at her. At that moment I knew strength is what she needed and the understanding that all was going to be ok.

From that moment, we have never ever looked back as a family. Evie has gone from strength to strength. She has achieved milestone after milestone. She has brought nothing but love and happiness to us all. Evie has taught us all to be patient, to be kind, to understand more and be considerate of everyone. She attends appointment after appointment and isn’t fazed, everyone that meets her can’t help but smile, because she brings such sunshine.

We had our daughter Halle in 2017, Evie was just over 1 when she was born. The girls have such a wonderful bond, they have missed one another tremendously over the past year of lockdowns. When they were reunited, they just ran at each other down the road and then dived into one another's arms. The girls bicker like sisters, but their love is pure. They really are the best of cousins.

When Evie was first diagnosed, the unknown was of course really scary, so many questions flew around our head. I am a teacher and I quickly set to work doing my research. I wanted to know all the ins and outs, the possibilities, have my questions answered and to be able to have some solid evidence and research to present to Sophie if she ever came to me with a worry. I needn’t have done any of that, Evie has just grabbed life by the horns and has been such a trooper. Her parents have equally been strong, supportive and such wonderful parents to Evie.

Being Evie’s aunty and uncle is an absolute honour, we are SO lucky to have her in our lives. We have made so many memories and we can’t wait for Covid to go away, so we can continue to make more. We have sleepovers and trips we want to get planned! Don’t be afraid, feel lucky and blessed, because that’s exactly how we feel.

A Sibling Story

By Summer, 24, sister to Mikey and Missy

My name is Summer, I'm 24. I have three sisters and three brothers, there are seven of us altogether. My two youngest siblings Mikey aged 10 and Missy aged 9 both have Down syndrome. They are just my brother and sister and I forget they have DS most of the time.

I was 13 when my mum received a phone call from her social worker telling her that a baby was about to be born and they asked whether she would take him, Mum was a foster carer and of course she said yes.

A few weeks later Mikey was born, and we got the call to tell us he had DS, we were asked if we would still take him.

We went to the hospital to pick him up when he was 10 days old, he was so very tiny. He was ready to go, dressed by the nurses, in clothes that had been left in the lost property box.

A few months went by and when it was decided adoption was what was best for him, we decided that he was not going anywhere, we completed his adoption soon after he turned two.

Everybody loves Mikey, he is so funny and gives the best hugs. I can honestly say he is the best thing that has ever happened to our family, we all adore him.

Mum decided to stop fostering to concentrate on bringing up Mikey, we soon felt we as a family had more to offer. Mum went through the adoption assessment again and we waited and waited. In 2015 we were matched with a baby girl who had DS, but so were another family.

Sadly, for us but happily for them they were chosen. We were

upset but we always say everything happens for a reason, so we waited.

In December 2016 Mum and I went to an adoption open day. It's a strange feeling, going to one of these. They make you feel horrible and sad, seeing pictures of so many children looking for their forever family. There's also the excitement, the hope that you'll find your new family member. We went to a table and were handed a photo album of a little girl who was not only gorgeous but also had a little extra sparkle.

Mum and I looked at each other and at the same moment said, "We can Just go home now." Mum phoned her social worker as we were leaving the building to get the matching process started. Missy, (not her real name) joined us in April 2018 after a lot of holdups. She is just perfect, she can talk for Scotland and never shuts up, she loves dressing up, Frozen and animals. She is a typical 9-year-old girl.

Our worry was how she and Mikey would get on, the second they saw each other they were inseparable. Missy does tend to mother him and enjoys nothing more than dressing him in her clothes, he is more than happy to let her.

I've told Mum that in the future they will both live with me, if they cannot live independently. To be honest, I will probably have to fight my other siblings for that privilege.

Having two siblings with Down syndrome is just the same to me as having siblings without, they may need more help with some things, we love them, so it's easy.

I have a baby of my own and they are the best uncle and aunt to him. I refused all of the unnecessary testing when I was pregnant. Mikey and Missy have shown me Down syndrome is nothing to be scared of, quite the opposite in fact.

A Grandparent Perspective

By Lynda, Nanny to Jessica

My name is Lynda & I am Nanny to 3 beautiful girls. Jessica was born in April 2017 just before 7am & I was so happy to have another granddaughter to join the 2 I already had. I went to the hospital later that day to meet her for the 1st time. When I got there my daughter was in tears having been informed, they suspected Jessica may have Down syndrome. At that moment all sorts of thoughts & worries ran through my mind, how badly would she be affected, would she walk or talk? As soon as I had Jessica in my arms for that 1st cuddle, I just knew things would be ok. Whatever life threw at us we, as a family, would cope. I was totally overwhelmed by the love I felt for this little girl with a mop of dark hair.

Fast forward 3 years & although there have been obstacles to overcome, any worries I had soon evaporated. Jessica is full of character & loves nanny cuddles, in fact nanny was 1 of her 1st words! She quickly developed her own personality & we all know what she likes & dislikes, she may not have the words exactly, but she can certainly tell you what she wants!

Jessica has reached many "stepping stones" rather than the "typical milestones" at nearly 4 she isn't yet walking but you only have to watch the determination on her face to know she will do it when she is ready. She loves swimming, something my daughter has done with her since she was only a few months old as a way to improve her core strength, she enjoys going to the park & being pushed on the swings.

Annabelle, Jessica's big sister, has always loved coming to stay with nanny & grandpa & this was something I was worried might not happen with Jessica but thankfully she loves it just as much, although I'm not sure if it is us or our cockapoo Teddy she enjoys seeing more. What Jessica lacks in size she certainly makes up for in personality & I always say she has a smile that can brighten anyone's day.

I have so much love for this little girl & when she holds out her arms & says “cuddle nanny” I wonder why I was ever worried about her quality of life. Yes, I want to protect her from the evils of the world but then I want to protect my other granddaughters just as much. We honestly wouldn’t change a thing about Jessica because if we did, she wouldn’t be the cheeky, fun loving little madam she is!

We found love because of Down syndrome

My name is Nicola, and my partner is Thomas. Our love story is unique.

In 2007 I became a single parent to my beautiful and very lively 3-year-old daughter, Jessica when things didn't work out between her dad and I. We ended our 10-year relationship somewhat acrimoniously and although she still enjoys seeing her dad at weekends, parenting her on my own made me and Jess inseparable.

We did everything together. Wherever she was, I was not far behind. I was lucky enough to be able to give up work when Jessica was born so my life was completely devoted to her from day one. I didn't know where she ended and I began. When we began our journey on our own, we clung to each other and lived in our own little bubble.

I was not expecting to meet someone who was in the same situation as me.

I had many unhelpful comments such as, “Who will take you on with a disabled child?”, and “Men don’t love other men's children”, but I didn’t care. If it ended up just me and Jessica for the rest of my life, I would have everything I needed. Until I received an email from a man called Thomas.

In 2009 when Jessica was 5, I decided to step out of my comfort zone and challenge myself to trek across The Great Wall of China. Jessica had not long had further emergency heart surgery and her bravery inspired me to be brave too. I was so proud of her and I wanted her to be proud of me too. I wanted to raise money for the Down Syndrome Association and for our local support group Down Syndrome Liverpool. And that’s where Thomas got in touch with me.

Thomas was a committee member of Down Syndrome Liverpool and was responsible for publishing stories in the newsletter and on the website. He emailed to ask if he could feature mine and Jessica’s story and hopefully raise the profile of the fundraising mission. After a few emails backwards and forwards I discovered that he was also a single parent with a five-year-old daughter called Charlotte and the girls were born with the same heart defect which needed open heart surgery and around about the same age.

Curiosity got the better of me and I did some delving online and the more I found out about Thomas, the more I was intrigued. Over the months the emails became less about the China trek and more about each other, talking to each other nearly every day, until he asked me out on a date. I thought he’d never ask!

We met in a pub in Liverpool on a cold and windy October evening in 2009 and we hit it off straight away. We nearly missed our meal booking because we were talking so much! We instinctively knew the light and dark of having a child with Down syndrome and we were both passionate about actively changing negative stereotypes of people with Down syndrome and supporting their families too.

The following weeks turned into months and it was time the girls met each other and despite our anxiety they got on like a house on fire! I heard Jessica whispering not very quietly to Charlotte that, “my mum likes your dad”. And that was the deal sealed.

We are celebrating our twelfth year together and although it is far from easy at times our relationship has withstood more extreme highs and lows than most couples will ever go through. The unspoken understanding of being a parent of a child with a disability is the strong foundation that we have built our life on and now we have a child of our own, Patrick. Patrick is 4 years old now and is very lucky to have two older sisters to care and play with, alongside Thomas’s two older children from his previous marriage, Thomas, 27 and Christopher, 24.

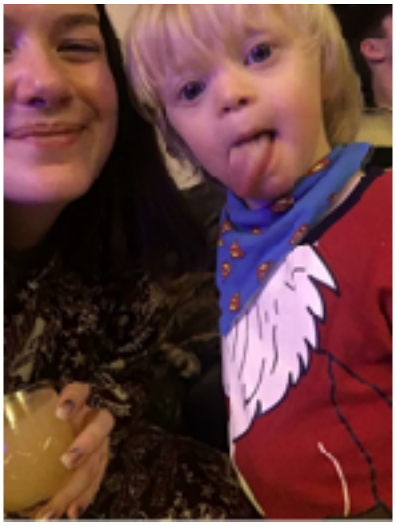
Meeting Thomas has transformed my very lonely world into one with vibrant colour, noise, laughter and most importantly love.

A Blended Family Story

From Katherine, mum to Eli

We are a blended family. My husband has 3 children from a previous relationship, I have 2 and together we have 2, including Eli who has Down syndrome. India, Eli's stepsister, aged 23, said "Having Eli in my life has brought joy, love, laughter and a stronger appreciation for all the little things. Yes, he may take a little longer to reach certain milestones in his life, but what does that matter when you see the determination in his every step. Eli has taught me that love has no expectations, and truly how many 4-year-olds can light up a whole room the way he does."

Anthony, Eli's stepbrother, aged 18, said "Eli is so cute, he is fun to be around and even though he doesn't talk yet he is happy and can make me know what he wants. We have done things that we wouldn't have normally done if Eli didn't have Down syndrome, thanks to support groups and charity groups he's part of. I even did some Makaton training so I could communicate with him, a skill I would not have ever thought about learning. Yes, his medical issues and hospital trips can be worrying but he is so brave and takes it in his stride, his strength makes me feel stronger. His smile is infectious and he's a joy to be around."



Jasper, Eli's brother, aged 6, said "It's a much better life for me to have Eli, he's happy, I like doing things for him. Him having Down syndrome is not a problem to me, he's a good brother. I get to do more things with him and with the special groups he belongs to. I love him so much and I will always look after him."

All the kids love him and would go out of their way to help and support him, he has completed our family and brought us all together as one unit, even though we don't all live together.

A Sibling Story

By Emily, sister to Evan

I’m Emily, I’m 29 and the little monkey in the picture with me is my little brother Evan who is 6 (yes there is quite a gap!). Our sister Elysia (who also had a high chance prenatally of having Down syndrome but was born with the regular number of chromosomes) splits the difference at 17 meaning there is an 11-year age gap between each of us.

I can vividly remember when and where I was when I found out Evan had Down syndrome. I was 22 (nearly 23) standing in our living room looking out of the patio windows on the phone to Mom to find out when she would be home and I could finally meet and cuddle my baby brother. After being told that they wouldn’t be coming home that day, Mom told me Evan had Down syndrome and that he’d be in hospital until he was ready to come home but that she didn’t know how long for. I remember feeling shocked and as soon as I got off the phone going straight onto the internet and Google. I wasn’t scared or upset. I simply wanted to find out more, that's just the way I am. I loved my brother already even though I’d never even held him or seen more than a photo and wouldn’t for another 11 days.

At the time Evan was born, I was working full time in a school as an NQT, Newly Qualified Teacher, and envisioned my future firmly in mainstream teaching. I’d been a supply teacher the year before and had even taught a class with a pupil with DS in there. I don’t remember much about her just that she went lower down the school for morning core subject lessons and came back to be with her class in the afternoons.

When I was at university, I did a week placement in a local special school and hated every minute. I couldn't cope with the smells of the nappies at changing time as anyone in my family will tell you I don't have the strongest of stomachs and even now I will only change nappies if I have no other choice. I felt lacking. I did not have the skill set to teach those pupils and felt entirely out of my comfort zone. Evan has changed all that. He's taught me patience, compassion and the importance of the word yet amongst hundreds of other things. He's made me a better person and a better teacher all by just being his adorable, cheeky self.

After teaching in mainstream schools for 6 years, late last year I accepted a teaching position at the special school attached to Evan's. I currently teach Year 9 pupils in a Moderate Learning Difficulties school and I couldn't be happier. I've found the perfect school for me and without Evan I wouldn't have known it existed. It's part of the same federation as Evan's school and shares the same headteacher. Our classrooms are less than 3 minutes apart, but we rarely see each other which is perfect. I get to pick him up on Fridays and pop my head round during school discos to see him having the time of his life or give him a wave and reassurance during fire drills when we line up on the same playground.

Without Evan I wouldn't be where I am now. I wouldn't have learnt Makaton or the importance of non-verbal communication. I wouldn't have the patience needed or such an in-depth experience of the EHCP process from the family side of things. Even teaching pupils with SEN in mainstream, if I've told parents of children in my class that my brother also has SEN they've been reassured, I get it: I understand. They've got someone they can moan about how long referrals take or how long it takes to fill in DLA forms because I've been there albeit not firsthand, but I've certainly helped Mom and listened to her moan enough!

Having Evan in my life changed me and our family for the better. I love him more than words can express, the same for my sister, but I've never been as protective over her. Evan needs me to help him, to fight for him and I will. He's my baby brother and even when he's being a pain by throwing my glasses and then running away giggling his head off, I wouldn't change a thing about him!

A letter to my niece

WCAT Blog

Dear Emma,

It’s been nearly seven years since you made me an aunt for the fourth time, arriving during an uncharacteristically sweltering Scottish summer. While your poor mum was spending the days before your birth desperately trying to find ways to keep cool in a heatwave at nine months pregnant, your aunties, uncles, granny and big cousins passed the time by having a little family flutter, making bets with each other as to what date you would be born.

Your due date was perilously close to the day I would turn thirty-five and I was hoping you would have the decency to leave a bit of daylight between our birthdays. I didn’t fancy my own big day being overshadowed every year by the perennially younger, cuter, Cancerian in the family. After each of us had made our predictions on what date you’d arrive, we’d moved on to some of the other unknowns, guessing whether you’d be a girl or a boy, what weight you might be, what names your mum and dad might choose for you.

Finally, the call we’d all been expecting came. (Four days after my own birthday, so thank you for that. Your spot in the will is guaranteed). You’d been born at 3.36am in the morning, a girl, weighing 6 pounds 5 ounces. You were called Emma. There was also some unexpected news: you had Down syndrome. While we waited to be able to visit the hospital and meet you, myself and your Auntie Ruth set out to become Scotland’s leading experts on trisomy 21, using only the power of Google. As the doctor in the family, your mum would usually have been first port of call for any health-related queries, but as she was preoccupied with recovering from childbirth and adjusting to the realities of parenthood, we decided to be good sisters, for once, and give her a day off.

There were so many questions and it felt imperative that we knew the answers right away. What did this mean for you? Were there any immediate risks to your health? Would you have to stay in hospital for a while? How might your life be impacted by Down's syndrome, five, ten, fifteen years from now? The IT guy at Down's Syndrome Scotland is probably still trying to work out what happened that day in 2013 when their website received a month's worth of hits in twenty-four hours.

A day later, I walked into the hospital room to meet you for the first time and the sight of you pushed all of those questions firmly to the back of my mind. They were still there, but I knew they would wait while I got on with the much more important business of getting to know my beautiful niece.

During those early weeks and months, though, I tried to learn as much as I could – from conversations with your mum and dad and a few too many visits to Dr. Google – about what life with Down syndrome might look like for you. It didn't take too long to understand the significance of those words 'might' and 'for you'. The more I read and the more I spoke to your mum about how having Down syndrome might impact upon different stages of your development, the more I realised that your path was just as unwritten as those of any of your cousins when they had been born.

Yes, having Down syndrome would impact your life, it was, and is, part of your DNA. But so is your mum's generosity, intelligence, diplomacy, grace under pressure. Not to mention your dad's ability to faff for Scotland, watch ten straight hours of golf without blinking and magically turn a one-day work conference into a three-day mini break. (Sorry Stu, but if you wanted compliments you should have asked your sister, not sister-in-law, to write this).

Like any child, you were that mysterious mix of inherited characteristics, individual traits and to-be-fulfilled potential that magically come together to make something unique. It was impossible, and seemed pointless, to predict how all of those things would interact with your Down syndrome to make you, you.

But all of the Googling, all of the conversations with your parents, all of the trying to piece together a picture of the person you might become, did, as it turned out, have a point after all. It helped me to realize that what I wanted for you was exactly the same as what I wanted for all of the children that had been and would be born into our family. To thrive.

Thrive. It's one of my favorite words, because it's the one thing that we can all aspire to and the one thing that, with the right support and conditions, we can all achieve. 'Excellence' ,'greatness' ,'brilliance': not everyone will accomplish these, most people won't, but all that any of us truly needs to be happy is to thrive. Succeeding, attaining, and finding fulfilment on our own terms, in our own environment, on our own time.

It's been nearly seven years since that particular lightbulb moment and I have to say, you're smashing 'thrive' out of the park. (You get that competitive streak from your mum's side of the family). Before I sign off, I wanted to let you know just some of the ways that you, Emma, are thriving. I can't wait to see where the next seven years will take you.

T is for Tenacious (definition: holding tightly onto something or keeping an opinion in a determined way). A vital quality for success and one that you have in spades. If you want to do something, or equally, don't want to do something, there is little that can be done to persuade you otherwise. So far, my record for successfully refusing to hand over my iPhone stands at four minutes twenty-seven seconds. I think that you would patiently wait for me to slip into unconsciousness before prizing it out of my hands, if it came to it.

H is for Hilarious (definition: extremely hilarious and causing a lot of laughter). You're definitely the comedian in the family, an admission that it pains me to make, as I'm pretty sure I held the title before you came along. Your skills for mimicry (taking the mick out of your elders, in other words) are unrivalled and your insistence on calling your Uncle Tommy 'Uncle Mommy' even though I know you can say it properly will never not be funny.

R is for Resilient (definition: able to be happy, successful, etc. again after something difficult or bad has happened). You've had a few hospital visits in your almost seven years on this earth, but I've never seen someone go so quickly from bed bound to terrorizing the nurses on the ward. Rumors that you occasionally fake illness because you have a particular penchant for hospital macaroni cheese are, as yet, unproven.

I is for Independent (definition: not influenced or controlled in any way by other people, events, or things). Sometimes, you just decide that if you want something done, then you might as well do it yourself. Sometimes, that extends to helping Granny get dressed in the morning because she's not going quickly enough for your liking. We're all pretending that's why she left the house the other day wearing a tutu and a Paw Patrol t-shirt that was two sizes too small.

V is for Vivacious (definition: a vivacious person, especially a woman or girl, is attractively energetic and enthusiastic). To borrow a phrase from an old 1980s movie that I will definitely make you watch when you're old enough, no one puts Emma in the corner. You have a knack of entering a room as if everyone has been waiting for you to arrive which, let's be honest, they usually are.

E is for Educational (definition: providing education or relating to education). You've taught me a lot: to hide my phone when you come in the room, as well as any chocolate I might be eating, and every single verse of 'The Wheels on the Bus', to name a few things. But, along with your mum and dad, you've appeared in campaigns for 'Wouldn't Change a Thing', smashing stereotypes about children and adults with Down syndrome and helping to educate people around the world, building a society that is more inclusive for everyone. You rock.

I love you, amazing girl. Auntie Annie xxx

A Cousin Story

I Met. I Saw. I Loved. by Erin 13 about Cousin Rosie

This week's blog was originally written by Erin McCallum, 13, as a personal writing English essay under the topic "Something that has had an impact on you." Erin is cousin to Rosie Bud McCallum, who features in the Wouldn't Change a Thing book for new parents. Erin is currently in second year at Prestwick Academy on the west coast of Scotland. She says she aspires to teach PE "to help young people with disabilities feel included and realise their dreams – just like everyone else".

The ringing sound that every kid loves to hear. Kids running out into their parent's arms. After a long hard day at school, I grabbed my mum's hand as she tells me she has exciting news. She made me try and guess all the way home to keep me entertained.

It was an early spring day; the sun was smiling, and the bad weather had gone to sleep. I remember being over the moon when I heard about the news. Getting shown pictures just made me so proud!

My grandparents were coming to collect me and take me to visit. By the time I got picked up it was around 7pm, which is very late to be going out for a seven-year-old! I remember feeling very nervous, I'm not sure why, but I was. I was in the car. It felt like my heart was pounding out my chest. I had butterflies. Crazy butterflies. We had arrived.

I started to shake – I honestly don't know why. My granny grabbed my hand to cross the empty road. The car park was dead. It was pitch black, and the only light was the light shining out from the windows inside. I was so nervous. I couldn't remember being in an environment like this before (although I had but I was still young at the time).

As we entered there were nurses rushing about here and there. Families were sitting nervously in the waiting room hoping they would get the news soon that a new life had been brought into this world. My heart felt like it had been pounding out of my chest as we arrived at the ward. Thump. Thump.

In these two small seconds many emotions and thoughts were rushing through my mind. We enter – there's my auntie, sitting on the bed. Her arms are around this tiny little girl. She and my uncle were so chuffed. I remember thinking she was smaller than normal, like really small.

We were introduced to her. Her name was Rosie. We all got a wee hold of her, and she was so tiny she could fit into one of my 7-year-old arms. I knew she hadn't looked like any other baby I had seen, but she was definitely the cutest. Her little rosy cheeks matched her name perfectly. Her little button nose was adorable. I overheard the adults talking about their worries and the uncertainties of Rosie and I wasn't sure why. But on the way home my granny and grandad were talking about 'Down syndrome'. I had no clue at that age what it was, I had never even heard of it before. They explained to me and I was shocked. I didn't really know how to react or what to do.

Fast forward 7 years. Of course, there were a couple of worries in my family about Down syndrome and being uncertain is a horrible feeling. There were worries like school, her learning, will she make friends? Of course, it's been challenging for all of us, but nothing better has ever come into our lives.

5 years ago, my Auntie, Uncle and three younger cousins moved into a house two doors up from mine. It's amazing. She's the best thing that's come into my life – for millions of reasons. She's changed me for the better and made me realise so many different things.

For one, I've learned never to judge anyone until you know them. I don't think of Rosie like she's got a disability. I see her just as I see anyone else. I've learned that there's a person behind every disability.

When I am older, I would love to do something that helps people – such as becoming a PE Teacher or a Fitness Instructor – and make sure that people who have disabilities have the same opportunity as anyone else. I want to make them feel included, because as they grow up, they will start to realise that they are different. I would love the opportunity to make them feel as important as everyone else and show them that they can achieve their dreams – just like anyone else can.

Rosie is now 7, still tiny, but she's 7. We see each other almost every day, but right now (due to the current lockdown situation) we shout across from our gardens and use FaceTime instead.

She's my best friend, and I know we'll grow old together as best friends.

A Grandparent Story

To Know Him Is to Love Him by Rita and Vijay, grandparents to Kush

As many grandparents are finally getting the chance to reunite with their grandchildren, today we hear from Kush's grandparents, Rita and Vijay. Kush is 7 years old; he loves music, reading and horse rides every week. He's a bundle of fun and makes his family laugh every day. He's doing really well at mainstream school and has an abundance of friends. He's the best big brother to his sisters and has a smile that could melt a thousand hearts. To know him is to love him. Thank you, Rita and Vijay, for sharing your story with us.

'In the old days we didn't have much knowledge about disability unless there was someone in your family who had a disability. Children were labelled and the family was left to their own devices. Ignorance at its best, didn't help anyone.

Sadly, it wasn't uncommon to completely ignore children with disabilities as no one knew what to say or how to interact. It's bizarre thinking about it now.

When Kush was born it was an absolute shock as we had no idea that he had Down syndrome. In all honesty I did not know much about disability as I had not come across many children with disabilities. I was really worried in the beginning, mainly about my daughter and how she would cope. It was my ignorance which increased my anxiety. If I had known about DS, then what I know now it would have really helped us all.

We spent a few months really worried about the future. Kush is an absolute darling; he is a happy child and has the most amazing smile which melts our hearts every time we see him.

Kush is very special to us. He has brought our family closer than I ever imagined possible. We are astounded with what he can do today. It might take him a little longer, but he has made amazing progress. His speech is coming on leaps and bounds and his clarity continues to improve. The help that we get in this country is amazing and we are really appreciative of that.

He does everything with his sisters and cousins and other children of his age and lives life to the full. We are just so proud of him. Kush is a magnet that brings people together. He is so happy and fun to be with that we forget all our worries and problems in life when he's around.

I worry about bullying in the future. The world can be very cruel, especially children in their ignorance and I would hate to see Kush having to face that, hence I feel that these campaigns which improve awareness, acceptance and promote inclusion will go a long way in eliminating negativity and hopefully bullying will not be a major problem. My daughter shares our journey together as a family with Kush on her wonderful Instagram page @t21teamkush. We couldn't be prouder of her and the wonderful community we are now part of, all striving to change mindsets.

Kush is doing very well at the moment and our hope for him is to be able to be independent, have a job and friends and be happy always. Our family will always be there for him should he ever need us and in turn he will always continue to bring laughter and joy and abundant happiness in our lives and in the lives of the people around him.'

That Zachary of mine

A Poem by Zachary's Nanny Sharon

My grandson Zachary is 6 years old.

He is cheeky, funny & full of fun.

He makes me so proud with all that he has overcome.

He is the best brother to have as their chum.

He is nanny's shining star and from school he received a golden star
for his amazing home schooling!

He is loved so much even when he FaceTimes me at 7 in the
morning.

So mischievous, so loving and kind

That Zachary of mine.

By Zachary's Auntie

When our nephew Zachary was born, we were very naive and had extremely dated knowledge of T21 so naturally we worried not just about Zachary and the life he would have but about his parents and his older sister. We felt guilty that we didn't live nearby so we could help out or be there for all of them. But 6 years on all we can say is how wrong we were! Zachary is an amazing little boy, and we are so proud of him every day! His cheeky face and his mischievous smile light up any room he is in. Zachary loves school and playing with his sister and brother. We can honestly say that we wouldn't change a thing, Zachary is a true credit to his parents and a very special boy who has changed our lives for the better.

A Sibling Story

My Sister by Nino Genua, age 22

Lia is my sister, my best friend.
My sister is beautiful, funny and kind.
She loves me, takes care of me and I take care of her.
We have grown up together and did singing, dancing and dressing up.
Lia helped me ride a scooter and go swimming.
She helped me learn lots of things and I love her forever.

My Brother by Lia Genua, age 17

Nino is my big little brother

He's always been there since I came into this world to look after me, care for me, play with me and make me laugh.

I love caring for him and he takes care of me too.

Having an extra chromosome doesn't change a thing about him apart from it makes him even more special in my heart.

He is the best brother I could ever have asked for; he amazes me on a daily basis with the things he achieves.

He has grown into the most beautiful young man, who doesn't let anything, or anyone, stop him living his best life.

He has the most caring heart and I am proud of him every day and he should always be proud of himself

I will always love and care for Nino, he is truly the best

A Mum’s Story

By Janie Adams

This is a completely raw and honest account of life with my 4-year-old son with Down syndrome. I am writing this because I wish I would have read it when my son was born. I am a 46-year-old single mum, whose son’s father is not around in his life, not because of his condition but for complicated reasons.

Going back to the day my son was born, he was rushed into the world by an emergency section, which is unusual and not related to DS. Tylar nearly died when he was born due to respiratory issues but after a couple of weeks, we were allowed home and he has continued to astonish me with how strong he is both mentally (super stubborn) and physically. During the emotional hospital stay away from home, I was sitting on the beach with my daughter having a short break away from the hospital and I saw an adult with Down syndrome. I actually cried for my son because this was not somebody I wished him to become.

Now when I see similar adults, I am super proud of them, because I realise firsthand just how much determination it took for them and their families to reach this point of independence. How much effort my son puts into learning to walk, talk, learning his alphabet, animal names and how his whole face lights up when he gets something right and is praised for it.

So, I'd like to say to any older mother who has a diagnosis and worried about not being able to cope or any other lone parents whose baby's father will not be around to help, you CAN do this! Obviously, as with any other small child, there will be days where you are shattered and need big amounts of coffee to get you through the day, but you can cope. In fact, more than cope, what you will realise when you have a child with Down syndrome, or in fact any disability, that you can thrive because you will become part of an extended family of other parents who support each other in a unique community and are there for you and completely understand anything you need reassurance with too.

My son has two older siblings, my daughter is 18 and I have an older son who is 28. I've done the whole parenting thing a couple of times and the main thing that is different with my youngest is probably how fiercely protective I am of him, he probably is slightly spoilt too, he looks way too sad to be told off and tugs on your heartstrings.

You know, society is the thing that makes everybody obsessed about looks and intellect, yet my son will not be under the same type of pressure to be a high-flyer. He can truly be free of societal norms and be happy to be himself. It's actually a blessing in that way. Wouldn't we all want to be in that position, I know I would.

In my life I have realised that there is always somebody worse off, I can't imagine being given a limited lifespan for my child of a few years or him not being able to run in the wind, watch his tic too, take his beloved scooter to the park or dance around to drag Queen songs. He has such a busy fun filled life and sometimes I feel like I could burst with pride watching him. Often, I look back on the very early days where I naturally grieved for the child, or life, I thought he was going to get but just like a set of scales, the more I got to know his cheeky personality, the less the grief got until it vanished completely.

I know it’s hard for people without a child with Down syndrome to believe that parents wouldn't change a thing, but if you saw through their eyes how much their child's barriers or small mountains, they climb to achieve things, yet they always do, you would realise they are blown away by their sheer determination and warm personalities too.

Having a child with Down syndrome will change you for the better, you become more patient, less concerned with other people judging you, more grateful for health and for everything you've been blessed with.

Please don't worry about the list of health conditions that Google will give you. Any child can go through many different health challenges, but you wouldn't have known that before they were born. My eldest was diagnosed with diabetes at age 16 for example. Also, many of the adults you see age 40 for instance have not had the benefit of advanced research. My son is in mainstream school and loves it so much, because he is smaller, the girls mother him and look out for him.

They know techniques to teach him relevant to him being a practical and visual learner. He honestly picks things up that I show him really fast, especially the things he shouldn't be doing. I know lots of other people who are practical and not academic and it hasn't stopped them either. Please just know, you are not alone, if you are judged then it will be by people you are better off without in your life. Nobody has judged or blamed me for being an older mother but most of the mums of kids with DS I have met are actually really young.

My son is a proper joker, he loves metal music, drums, spicy food and animals, he is really attached to his sister and looks up to his brother. His sister says she has changed for the better because of him too. It really helps your other kids have more empathy for other people in life going through any type of challenge. It's truly a blessing.

A Sibling Story

By Lewis Toal aged 21, about his sister Emily aged 10 and Brother Callum aged 15.

I was eleven years old when my mum told me that she was having another baby brother or sister. I was so excited because this was something we had all been waiting for.

When Mum met Dad, Mum and I had just been us two for seven years and when I met my dad (that's how I know him now) he was amazing, he was so much fun, and he also had my wee brother Callum which made us just feel like a family.

We went on a good few holidays all together, mostly to caravans in Scotland and we just had the most fun but when Mum told me she was having another baby it just felt like this baby was the one thing that would pull us all in together and connect us all.

I remember while Mum was waiting for the baby, she told me that the baby had Down syndrome but she and Dad were happy, so I was happy too!

I knew that once the baby was on its way, I was to go to my friend Bradley's house and I came home one day and Mum was in the kitchen – Dad was away to get Callum to come and have dinner.

Mum was way more irritable than she normally is and she was asking me to make sure my rucksack for Bradley's was packed. I remember asking her if she thought she might be having the baby and her telling me she thought it might happen soon.

Callum and Dad arrived back and I was 11 and was really aware that Mum seemed to be in pain, so I got my wee brother into the living room and put the TV on really loud. Really soon after this my dad came in and told us my mum had had my baby sister and they were upstairs in the bathroom – we both went up and got to see her and say hello. She just looked completely beautiful!

My little sister Emily struggled a little for a few days before coming home and I was so worried about her but once she was home, I just loved being her big brother so much! We formed a bond that will last us a lifetime. Callum was the same and they have an amazing relationship too but like any family, their relationship is their own one in its own right.

She was the amazing little sister that just bonded us all together. Emily has had heart surgery twice and this worried me so much each time but my mum and dad made sure I was able to see her as soon as possible and I'll never forget how she reacted to me. I felt like the most important person in the world.

When I was 14, I was looking after Emily for 15 minutes while Dad took Callum to sports camp. I was carrying on with her when she suddenly just fell over like she had just lost balance. I laughed at first but every time she tried to stand up, I noticed that she kept falling down to the same side and I realised something was really wrong with her, her face looked strange too.

I called 999 to get an ambulance for her, then called Dad to tell him what was happening – he made his way immediately back and left to the hospital with the ambulance while I tried to get Mum at her work. My wee sister had had a stroke, again I was so worried for her but Mum and Dad made sure me and Callum were included in everything and when she came home a few days later we felt we could cope with anything even though she had to get injections and daily exercises. Emily is 10 now and nothing can stop her.

She is very feisty and when I have to be firm and put her in her place she sometimes cries because we are so close, she hates for me to tell her off. Callum and Emily are closer in age and have a much more fun relationship but we are all really close together and she is definitely the one who pulled us all in together.

I'd love to say my sister is some kind of out of the ordinary girl (which she is when you look at what she's been through in hospital) but really, she is just my wee sister just like any other wee sister.

We love her but we fall out like any other siblings!

A Sibling Story

By Emily, sister to Daniel & James

My name is Emily and I have two older brothers called Daniel who is 16 and James who is 15. My brother James has Down syndrome. Daniel is very clever and funny. James has a great sense of humour and is caring. I think we are just a usual family. On a typical chilling out day you will find us all doing our favourite things. James likes to listen to music, cook and walk Grandma's dog, Daniel likes to do exercise and online gaming with friends and I like to read and be creative. We do things together too though! James and I watch the same sort of TV and both do Karate and James and Daniel like to joke around like boys do and also both like gaming. We all love swimming! At home we sometimes do things a bit different to other families because James sometimes needs a bit of extra help or time but usually that just makes it more fun! More time to have a laugh!

Our family are big Lego fans but I have to say James beats us all when it comes to sets! James has nearly all of the Marvel Lego sets there are! He even has the massive Heli carrier! I like Harry Potter Lego sets Daniel likes the collectible series. We all like the same sort of things but like other brothers and sisters we like our own versions! We all love Marvel. There is so much to talk about and James knows so much! His memory is amazing and I can ask him anything about the characters but his favourites are Iron Man, Thor or Spider Man. We have really enjoyed watching and re-watching all the movies during lockdown.

We are all music lovers and James enjoys listening to music on YouTube and his favourite artists are Taylor Swift, Olly Murs, Bruno Mars and of course Beyonce! He loves to have a dance and sing along to tunes on the radio and prefers to go in the car with Dad because he lets him turn the radio up really loud for

what he calls ‘his tunes’.

Another thing we enjoy doing together is an online quiz every week with other families. James and I enjoy seeing our friends online! When it's our turn to do a question round James has lots of good ideas for guess the Lego mini-figure. James loves being with people and socialising which is why he loves the online quiz. When the rest of us are in our slobs, James loves any excuse to dress up smartly, especially for online events or lessons! James’s look of choice is a nice pair of jeans and a smart shirt, which suits him very well. He loves to dress smart. Mum and Dad say he is a typical teenager. He also spends ages in the bathroom and often gases us with enthusiastic spraying!

The 3 of us will all have been to the same schools. Next year I will be with James in high school. James will be Year 11! I haven’t been with James in school but I know that all his old teachers loved him because they still ask how he is doing and tell me to say hello! Sometimes it is like having a superstar for a brother. Daniel is only one year older than James, so the boys have been lucky and been in the

same school a lot. I asked Daniel to write me something about James in school and he wrote: "I think James has always enjoyed school. He hasn't had to depend on me or anything like. He is very independent. The minute we arrive in school he's off to meet his friends. James follows all the school rules and routines without fail every day and is always eager to get to his next lesson. It's great for me to see that James gets along with so many people. He enjoys spending break times with his own friends and will sometimes ignore me! Other times their group will join me and my friends because we all know each other. We all have a laugh and a bit of fun. Everyone knows James and will give him a nod or wave around school or when we are out and about. I'm very proud of my brother because he gets on with it and James's positivity towards school radiates across the school."

Living with my two brothers there is never a dull moment. They are both typical teenage boys – they can be cheeky, silly and fantastic. Sometimes James can be a little bit extra of each and can be a bit stubborn but then so can I. James is great company and a great friend. I wouldn't be the person I am today without my brothers, both Daniel and James. They are both great.

(Mum note: Daniel asked what Emily's question about school was for. We explained it was for a book for parents as one of the things that parents worry about is the impact having a child with Down syndrome will have on siblings. His reply was "Why do they do that?")

A Single Parent Family Perspective

By Wendy, Mum to Elijah

Elijah was born on October 30th, 2013, not quite scary enough for Halloween. He weighed just 5lbs 12. He was tiny, my first thought as I cuddled him for the first time was ‘God he looks like his dad’. Probably not quite what you were expecting but as a single parent, looking like his dad was the last thing I wanted.

I was a blur of confusion, exhaustion, lack of sleep and emotion as he was whisked off by the midwives as he had turned blue, they muttered something about Down syndrome which I chose not to acknowledge.

At around 3am I finally went to bed; I’d had a shower which left the cubicle looking like a scene from Dexter and I felt like I had been run over. Not much sleeping was done, although my sister said at one point I was snoring, but so did she so, whatever. My head had been awash with thoughts, not all of them good. What did Down syndrome really mean for our lives, and could I cope, especially as a single parent?

The hospital ran some tests and two days later I received the results which confirmed he had Down syndrome. The nurses kept asking me if I had any questions, I had no idea what to ask, where to start, what to do. I was terrified. I was confused, elated, sad, happy, I was on a massive rollercoaster of emotions. We were on special care for nearly 3 weeks, there were many times I would sit in that little room, giant tears rolling down my face, looking at this helpless little boy hooked up to all sorts of monitors. He went through so much in that hospital, the nurses took wonderful care of us, but Elijah had a cannula, he had tubes taped to his little cheek, his feet were shredded to ribbons from all the blood tests, he was taken to LGI for scans, the lot. It broke my heart, yet he was so brave, he barely whimpered. His strength of spirit showed me what a little fighter he was and he deserved a mother who would fight for him. Holding him tightly I would gaze into those dark, dark eyes like pools of water with moonlight reflecting off them, I could lose myself in those eyes. At times I would miss him, even though I was in the same room as him, even holding him I didn't feel like I could get close enough, I needed to climb inside him and I realised, this little boy would change my life.

After 17 days on special care, we were allowed home, and that is where our adventure really began. This little man has gone from strength to strength. And because of him, so have I. He is my teacher, my inspiration, my guiding star.

My son has Down syndrome, and I wouldn't change a hair on his perfect little head.

As the months went on, I slowly learned that all the hopes and dreams and fears I have been the same as any mother, would he do well at school, will he be bullied, will he be able to stand up for himself, will he get married, and most importantly will he be happy? Maybe I have more reason to worry than others, maybe I don't. I can't predict the future but what I do know is that as long as there is breath left in me, I will do my best to make sure he is happy and achieves his goals. I strongly believe that children are a product of their environment, tell them they can't and they won't. Children need encouragement, guidance and love and, if they have that, they can accomplish anything and when he falls, I will be there every step of the way to hold his hand and pick him up.

Parenting is tough, single parenting to a child with additional needs brings its own challenges. I'm lucky that Elijah sees his dad regularly, so I get a break and Elijah gets a break from me. However, his dad and I do not get on, so when it comes to decision making, or discussing challenges, it's very much a one me band (and no that's not a typo!). When we go out and about ourselves, it can be quite problematic. Elijah is stubborn to the core, throughout his young life I have wanted him to feel confident making some decisions by himself, sometimes that is now to my detriment. On walks out, if Elijah wants to go one way, despite me telling him all the fun stuff is the other direction, he will run off to go where he wants. If we are eating in a restaurant or outside, once Elijah is done, he's off. I frequently have to abandon all our belongings to go and retrieve him kicking and screaming so I can pay the bill or gather our stuff up. Or there are occasions when he practices the old 'flop and drop'. He once lay down on some high up play equipment and refused to move. Kids couldn't get past him, or they were climbing over him (this is in the middle of the global pandemic), I had to climb up and manoeuvre him to the side but there was no way I could get him down safely. I had to rely on a kindly stranger who lifted him down for me.

So yes, life can be difficult. But that is life. I frequently look after my niece, she's four and a hilarious nightmare. In many ways, Elijah is easier than she is, my sister is not a single parent and they both struggle at times with this precocious youngster.

What I'm trying to say is that everyone has challenges, no matter who or how many in your family unit. But what I know is that it is most definitely worth it.

My son makes me proud every single day and through him I have found an inner strength that I never knew existed. I am on a mission to show the world that Down syndrome is nothing to be scared of it is a medical condition, an extra chromosome. First and foremost, he is Elijah, Down syndrome is part of him but it doesn't define him.

My son will never be a disappointment to me, I can only hope that one day I can make him half as proud as he makes me.

Elijah, my son, my world.

A Family Story

Mauger Family

I was born in Fukuoka which is on Kyushu island in Japan. I met my husband, Jo in Fukuoka in 2007. Then a couple of years later, we married in Japan and we moved to Guernsey where Jo is from in 2009.

In 2013, I got pregnant with our first daughter Ellie. That was a pure thrill for us and also our family in Guernsey and Japan. My grandmother in Japan, who I was very close to, was particularly over the moon. She was a classical Japanese dance teacher, and she was already talking about buying a Kimono for her first great granddaughter. But then after all the excitement, I remember that I was suddenly very worried if I would be able to have a safe pregnancy and labour in a foreign language. I was 29 years old at the time, by the time most of my friends in Japan had one or two children already so my friends shared their experience and assured me and it was helpful. Then when Jo and I went to see the midwife for the first meeting, we were asked many questions about health and background. Then one thing came up as a controversial topic between us. It was the question of if I would take a test to detect Down syndrome. Midwife told us that it's very normal to take the test so it's worth taking it. I said to the midwife I would decide later, in my mind, I had already made my mind up as I would not take the test because there was no point that I wouldn't give up my baby whatever the result, but I wanted to check with Jo how he was feeling about it. At home we discussed it and he said he wanted me to take a test because he didn't know if he had the confidence to raise a baby with special needs. In the end, we came to the conclusion that I would take the test but that no matter the result that I wouldn't give up our baby. The result was negative. So, we didn't talk about Down syndrome after the test.

In the early spring of 2014, I became a mother. It was 16 hour long labour and it was a natural birth. We named her Eleanor and even though I loved the name, we already decided that we will call her Ellie because we have similar name in Japanese and it's easier to say in both English and Japanese language. Ellie was so beautiful and perfect. I couldn't take my eyes off her. My husband, my mother, who were supporting me during my labour, and I all instantly fell in love with Ellie. I was holding her on the hospital bed and she stared at me with beautiful brown eyes and she moved her little lips and showed me she was hungry. My mother and my husband were laughing together and we were saying Ellie was hungry and we were full of joy. A couple of weeks later, my mum went back to Japan and Jo took paternity leave for a couple of weeks and he went back to work shortly so I became alone at home at daytime.

But a serious concern was coming up. Ellie was born at 7.5 pounds, but she was losing her weight and nobody knew why. The health visitor said maybe she had a feeding issue, so I was recommended to go to breastfeeding specialist. Ellie was a very sleepy baby and she fell asleep as soon as she started sucking my breast. The specialist was calling her a "lazy baby" - I was shocked that she started hitting her hard to wake her up! She was only a few weeks old and it was terrifying to see and I never visited her again. When she was two months old, one morning at 2am, I noticed something when I was breastfeeding. She looked like she had Down syndrome, but I was thinking at the same time, the test came out as "negative" ... but my instinct was telling me that my baby had Down syndrome. Our health visitor told me to take Ellie to GP to check if everything looks ok. I took Ellie to 5 different GP and my husband took her to one GP, so we took Ellie to the GP 6 times in total. When I took Ellie to the GP, I told her how I was worried about her weight loss. The GP always said, "Your daughter is absolutely fine, don't worry." Then I said to the GP that I have a strong feeling that Ellie has Down syndrome and their answer was always "You are too tired, get some sleep and rest". On the way home with Ellie from the 5th GP, I thought I finally went mad because it was only me who could see Ellie that she has Down syndrome. My husband did not see it either.

Then the one time my husband brought Ellie to the GP by himself, he mentioned that I thought Ellie has Down syndrome. The doctor checked her and said again that he wasn't concerned. On the way home in the car, my husband received a call from the GP. He said something was bothering him and he wanted to take another look at Ellie. He checked her again and said he thought that she was fine, but that Ellie could take the test just in case.

A week later, I got a call from the hospital. The specialist was telling me that my husband and I have to see her as soon as possible. I was in the office, so I spoke to my husband and we went to the hospital. Ellie was in nursery that day. When my name was called, we walked into the specialist's room. We sat down and the specialist said that she had received the result of the Down syndrome test. My heart was beating so fast. Then we heard that Ellie was diagnosed with Down syndrome. I was sobbing and I couldn't hear much of what the specialist was saying. My tears were not desperation or disappointment, but it was pure relief. I was not mad! Then the next feeling came, it was concern. What was waiting in Ellie's future? I asked many questions about how Ellie would be developing and the specialist couldn't answer anything, she was saying "I don't know". It made me suddenly worried so badly and suddenly I felt I lost our future. I thought I was ready for this but perhaps I was not.

That night, I could not stop crying, I was feeling sorry for Ellie that I couldn't give her a healthy body and let her have life like my friend's children, "normal life". I was also very scared of Ellie's unknown future. I remembered the day I had a daydream about Ellie's wedding ceremony, I heard on the radio the song 'Thousand Years' by Christina Perry and I was thinking the song was absolutely perfect for her wedding day. I was fully pregnant at that time and I was so excited to think about her wedding and many more dreams with Ellie. Someday, she would find someone special and spend time happily rest of her life. But that my small daydream was disappearing from my mind. At that time, I had never heard that someone with Down syndrome had a partner and married happily. I felt like one by one my little dreams for Ellie were vanishing. Ellie was always Ellie and she didn't change anything herself but just she had extra information about her that she was born with Down syndrome. My husband Jo also cried but he didn’t cry in front of me, I asked why he didn’t cry at the diagnosis day and he said because he wanted to be able to support me. Jo was shocked about the new discovery about Ellie, but he was fine with that. I asked why he could accept Ellie's diagnosis and he said “Ellie is already my daughter; nothing will ever change that even if she has Down syndrome. I love her as much as I did yesterday.” His words gave me so much relief. He was the one who was worried about raising a child with Down syndrome but 6 months later he had become a wonderful father. I was the one struggling, but it wasn’t about Down syndrome but more about what sort of future is waiting for Ellie.

A few days later, I finally settled, and I started researching Down syndrome. When I opened one of the websites to support mothers with babies with Down syndrome, I saw the message I had been looking for. “Congratulations, welcome to the world little one” It was my first “acceptance” experience. I finally felt real relief that there is a place where I can accept Ellie as who she is. Just this short lovely message made me very happy. I had my 30th birthday a few days later and Jo organised a surprise party at our place. We had a great time and I announced Ellie's diagnosis to my friends. I heard some unexpected comments. Some people said, “I’m so sorry to hear the news” and one of the guests who had a baby who was the same age as Ellie said to me, “My daughter will still be Ellie’s friend”. Down syndrome makes people think “sorry”. I was really sad, Ellie hadn’t changed and I realised these people were the ones who had changed after hearing Ellie’s diagnosis. From this experience I learnt how much the word “Down syndrome” has negative connotations for many people.

After the diagnosis, Ellie had to take various tests to check her health. A week later, Jo and I had a call from the hospital again. I instantly knew it wouldn’t be good news. We walked into the meeting room in the children’s clinic and we saw the same specialist who diagnosed Ellie’s Down syndrome. We greeted each other with a smile and the specialist looked worried. “I’m so sorry to tell you but Ellie has leukaemia, it has not progressed, but we need urgent treatment as soon as possible.”

I felt that someone had shot me in the heart and punched my head really hard and I could not breathe. The specialist was almost crying. I left the room, and I went to toilet shouted and growled like wild animal, it was literally heart breaking. “Am I losing Ellie?” that question in my mind made me feel desperate. I don’t know who I was asking for but I was thinking “Why wasn’t it me instead of Ellie? If it would make her healthy, please take my life!” It was the worst day of my life. My heart was breaking into pieces. Again, Jo was feeling strong and he tried to support me.

It was the second week of October 2014. We were going to travel to Manchester to visit our friends next day to have a long weekend but instead, we packed everything and we left Guernsey on Monday for Ellie's 4 slots of chemotherapy in Southampton Hospital. We sometimes returned to Guernsey, but we spent 6 months in Piam Brown Ward which is a children's oncology department. The first and second week I couldn't sleep at all. As a Japanese person who had only seen such a big hospital in film or TV drama, the hospital looked like a film set for me. Looking at the uniformed staff kept reminding me that my favourite TV show was ER.

Between the bad dream and the new and difficult reality, I was trying my best to understand what was going on with Ellie and what's going on in my life too. The 6 months of treatment were very tough. However, Ellie was always our hero and our sunshine. Even when she was having the treatment, she never stopped growing and developing. The head nurse was saying that she kept surprising her with her development and growth. One day I popped out for a shop while Jo was sitting with Ellie and when I came back to her room, she was sitting by herself! I was so surprised and so happy and so proud of her. That was when she was 7 months old. Then she stood up holding our hands or the hospital armchair when she was 9 months old. Even though she was feeling sick at dinner time, she never forgot to eat her favourite dessert or yogurt. She never let the leukaemia win. It was a battlefield, all the children we met there were just amazing warriors fighting for their life. Ellie was fighting for her life too.

When Ellie left the battlefield and came home, she was 1 year old. There was just a little hair left and she had a tube in her nose and line on her chest. 4 years later when she started her school life, she completed her remission and she beat leukaemia officially. It was one of the best days and whole family in Japan and Guernsey were full of joy and it was a huge celebration. I was ever so proud to be a mother of an amazing warrior and I will surely be proud of her for the rest of my life.

Ellie is turning 7 next month. She adores her little sister and she is currently helping with her little sister's potty training! She is a happy jolly little girl who likes tennis, piano, dancing, party, school and music. She has a best friend in school and she is surrounded by wonderful teachers and friends. She was born in a multicultural environment and she understands Japanese and English. She has been to Japan 5 times and she loves Japanese food! I want to say to myself 6 years ago, "Don't worry, many amazing things are waiting for Ellie! She will travel to many countries and will love Japan! So, don't worry." 6 years ago, some people said to me "I'm sorry for the news", I want to say "There is nothing to feel sorry about. Ellie will thrive in her life with joy and happiness." And so, she is. This is our story.

A Sibling Story

Life with Wilf, by Evelyn, 17

Being from a family of 8 children is awesome but having Wilf as a little brother makes it so much better.

He is the light of everyone's life. I have never met such a wonderful little character. He honestly is such a little ball of joy, brightening every room up when he walks in. I couldn't imagine life without him. He completes our family. We all love Wilf the absolute most and his perfect little smile.

When we first heard he has Down syndrome, I didn't know how I should feel. I didn't know if I should be scared or worried or even upset, but it wasn't soon after till I knew I shouldn't feel any of them. He is perfect. I am almost glad he has his extra chromosome; it makes him extra cool and extra amazing. Life with Wilf is a better life.

A Sibling Story

Story about Ivy & her Siblings by Mum, Lindsay Filcik

Ivy is our youngest child and has two older siblings. When we first learned of Ivy's diagnosis, I remember worrying about Zoe and Eli. I worried that they would resent having a sister with a disability. I thought they might not bond with her in the same way. We told them about her extra chromosome before she was born. They were only 3 and 5 so their understanding was limited. We read books that helped explain it. Zoe asked, "Will I still be able to hold her?" and "Will she smile at me?" and I realised that to them, Ivy would just be their sweet, tiny baby sister and that was enough.

When they first met Ivy, my heart nearly exploded. I could see how immediately they fell in love with her. They didn't see her as different. They saw her as beautiful, adorable, and wanted. They sang to her, held her and played with her. They have celebrated every single milestone as much as her dad and I have. When Ivy took her first steps, all of us were in the living room together cheering. It has been so beautiful to watch their relationships grow.

One of the best things that Ivy has done for her siblings is taught them that different is beautiful. She has normalised disabilities for them as just a part of humanity. They are more kind and inclusive because of her.

One night at bedtime, Eli was hitting his dad with his stuffed animal tiger. Sam asked "Eli, does Tigey need to go to time out?" Eli responded right away by saying "Dad, Tigey has autism and that means he sometimes has a hard time with changes. He wasn't ready to go to bed so he's struggling and that's ok. We have to help him." I overheard their exchange and my heart melted. This is Ivy's doing. She has given him such a big heart towards all people but especially towards people with disabilities.

One of my favourite things to do is introduce Ivy to other kids to teach them about Down syndrome and how to treat people who look or act differently than them. When Zoe was in 2nd grade, I brought Ivy into her classroom.

Zoe read a book to the class about Down syndrome and then we had a discussion with the kids. Zoe was so proud to show her sister off. At the end I let the students ask questions. One little boy raised his hand and asked Zoe "How come you got a sister who has Down syndrome?" Zoe smiled and said, "Some families are just lucky I guess!" Since the moment Ivy was born, I knew deep in my bones that I wouldn't change one single hair on her head or chromosome in her body. As we've grown as a family and I've watched Zoe and Eli love their sister deeply. I know that they would say the same thing. We truly are the luckiest!

Family Story

Written by Carole and Dave, Nanny and Grandad to Summer Leigh

The 18th of February is a day my husband and I will never forget. It is the day we welcomed our 3rd and 4th granddaughters into the world. Summer was born in the morning to Leanne and my oldest son Barry. Barry had testicular cancer in his 30s but we he was at the age of 42 becoming a daddy to Summer.

Isabel was born in the afternoon to my youngest son, but it is Summer I want to talk about you see Summer was born with Down syndrome, my thoughts on that day were, well she must have been sent to us for a very special reason, and she has been a delight from day 1 always a smile and a contagious little laugh.

She is so funny the way she dances and her ability to pick up a tune is second to none.

Beware, she has a wicked little smile and you know she's thinking about what mischief she can get up to, we have become very adept at catching things because if Summer gets to it first it gets launched and by it I mean it could be a cup or lamp and definitely her toys but we know the signs now so hide things before she comes.

Summer loves her food and it's lovely to see nice clean plates unlike my other grandchildren who always leave food. Summer gets on very well with her older cousins but does like to boss them about but it's always done in a fun way. Summer loves being part of the gang. They are all very caring with Summer and always look out for her.

Winter times are a worry for Summer and always tends to get nasty bugs but she always bounces back.

One day the unimaginable happened and Summer was diagnosed with leukaemia. I thought my heart was going to break and the initial months of her treatment were heartbreaking to see her so poorly. Summer is such a brave little girl and on her good days she is back to her smiley little self.

She is still undergoing treatment and to see her with her hair growing back and high energy levels I am so proud of her and her mum and dad they have been so brave and surrounded her with so much love as have her older siblings.

Summer is the most beautiful little human being I have ever met and when she was first born, she gave me the courage to carry on as I was undergoing chemotherapy for cancer. Summer has brought so much joy to our family and we couldn't imagine life without her, she is one feisty little girl, she's our Summer.

A Sibling Perspective

By Grace, Daniella and Chloe

From Grace

"Chloe has taught me to laugh at the little things and make every moment count. Most of the time she is an annoying big sister always telling me off for everything but she is always the big sister who wants to be involved in everything we do. Chloe has also helped to shape me into the person I am today. She has been a major influence on me and I am proud to call her my big sister. Chloe has done so many things I'm too much of a baby to do like climb the o2. She is strong, bossy, clever and fearless and I'm very thankful for everything she has taught me, shown me and will continue to do in the future. I love her so very much."

From Danielle

"Ever since she could walk and talk, my big sister Chloe has been the outgoing, loud mouthed, boisterous member of the family where her bubbly personality, unique sparkle and dry sense of humor has the ability to make everyone around her feel joy. She is just Chloe to me - my big sister- not an adult with Down syndrome. Chloe has done so many amazing things in her 23 years, from indoor skydiving to volunteering at a local cafe. One of Chloe's biggest achievements is completing her Makaton training. I am so proud of her and I love her so much for all she has done to change my life. Chloe is the single most influential person in my life from whom I have learned patience, compassion and complete acceptance. My life as a sibling of a person with Down syndrome has not been a life overshadowed, or a life filled with worry, or a life restricted. It has been a life enriched, a life open with possibilities, a life filled with a little more happiness."

From Chloe

"I love my sisters so much. Danielle helps me to do things and helps me when I don't understand, she looks after me and makes me feel safe. Danielle takes me on holiday, to night clubs, to restaurants we have so much fun, sometimes she tells me off and that's annoying, but I love her still lots. Grace is my little sister, and we help each other. Grace does make up with me and plays pool with me. She helps me with things like Instagram or if I've fallen out with my friend and I help her when she's feeling sad. Sometimes she's annoying but that's ok. My sisters are my best friends and I love when we can all be together. I think I have the best family and I love them so much."

Sibling Story

By Annabelle, aged 10, sister to Reuben, age 7

When I was 3, my mom said I was going to have a wee brother. I wanted to tell everyone! I would have someone to play with me every day.

The first day I saw Reuben, I remember cuddling him. He was so small and cute! I couldn't wait to get him home so I could take care of him.

Mom and Dad were very busy with the new baby and sometimes I wanted them to spend more time with me. When I talk to my friends, they say the same about their little brothers and sisters. When he was little, he couldn't do very much. Babies aren't very exciting when they're little but he was cute and cuddly and I loved him every day.

Growing up, I think we were like most brothers and sisters. I remember painting his face as Mr. Tumble. I remember swinging with him at the play-park. I remember dressing up for Hallowe'en with him and helping him to open Christmas presents. I remember holidays and parties, friends and family and I remember fights and being fed up and wanting my own space. I remember lots of fun and laughs and cuddles in the night, and how special he was to me.

When Reuben started school, I was worried because he couldn't talk much. I followed him around the playground and wanted to take care of him. Soon enough, he had his own group of friends and didn't need me but he still played with me and came to see me at break time. I read to him and helped him with his schoolwork. Having Reuben helped me understand that there are lots of different kinds of kids who can do lots of things. I think I am kinder because of him.

A Mothers Perspective

By Dawn, Mum to Maisie

I always found Maisie different to other babies and children with Down syndrome we have met, even at our local Foyle Down Syndrome Trust Group.

We had lived experience of a neighbour's gorgeous little girl who grew up with us BUT in truth I am still learning about Down syndrome and I always will be. Once you have met one person with Down syndrome you have met one, they are all unique and original just like you and me.

The difference in Maisie is her extreme hyper-mobility and hypotonia (low tone) it takes so much for Maisie just to regulate her body before she can even start to learn a skill.

Maisie is strong, independent in mind and has a fierce determination coupled with a mischievous, rascal nature. She requires help in everything she does to help her achieve.

It is thought that you must walk before you can learn and our Ms. Maisie waited till, she was 6.5years to take a few steps then at 7 years we thought she was going to walk but it regressed and now at 8 years we have a walker not like you and me but in pure Maisie style she is getting there. She cannot run, jump, skip but what she can do is heavenly to watch her determination, her charm. She may never do what others find easy but she can do it in true Maisie style.

Maisie has had every opportunity every child gets growing up. We went to Jo Jingles to baby groups, but we have always been different from her peers. They pass her by while they were sitting and crawling Maisie was lying on a mat watching them, but she still joined in. We brought the things to her and she shook instruments, cooed and had the most fun.

We have had every piece of equipment: standers, walkers, trike, feeding chairs, shower chairs, wheelchairs, buggies. Maisie will be independent as only she knows how and we work on having fun to learn.

We loved Maisie before we met her, and even more when she arrived. She had a rough start to life, and we spent most of our time in hospital as a family. Our boys were 8 & 9 years old and they enjoyed Ms. Maisie cuddles (they really are the best), carrying on with her and wrestling, doing what big brothers do, even calling her Crazy Maisie when she would do gymnastics off her baby mat, using her legs like hands instead.

We have a great life even with our challenges. Maisie was described as having a severe learning disability before going into P1 and it floored me to be fair. But it will not stop us doing everything to help Maisie learn and enjoy life.

Maisie loves water, music, Jo Jingles, her trampoline, her swing and slide and all things sensory. She, like me, loves throwing her head back in the wind and looking up to the sky or looking behind you whilst the swings in motion.

Maisie is amazing, she loves truly, madly, deeply and her zest for life is infectious, she has an aura that entices people to her and she brings out the best in everyone.

So, if your child is like Maisie you are in for fun, crazy, madness with mischief thrown in for good measure but just know we are here if you ever need us cause the challenges sometimes get a bit much but there are always ways around every situation and we will always overcome them no matter how big or small.

So, be more Maisie, see the world in its best light with no inhibitions, be free and enjoy the adventure. Mum x.

A Single Mums Perspective

By Emma, Mum to Ada-Grace.

(Follow our journey on Facebook and Instagram by searching for 'The Amazing Adventures of Ada-Grace')

I'm Emma, lucky enough to be a single mummy to the amazing Ada-Grace, who is rocking her extra chromosome and I wouldn't change a thing!

I was informed at my 12-week scan that I was considered "high risk" of having a baby with Down syndrome, but I made the decision to decline the invasive testing, as it really didn't matter to me if my baby was going to be upgraded to 47 chromosomes. I've been a single mummy since that 12-week scan, but I've never been alone in sharing my wonderful little girl with the world. We share our home with Merlin the dog, who Ada-Grace loves to terrorise and Nanna and Grand-pops live just along the road too!

Ada-Grace was born in January 2020 and spent the first 2 weeks of her life in NICU with a bit of a bumpy start. However, it didn't take long for her extra bit of sparkle to shine and she decided after spending time in the red room, she would completely skip the blue room and go straight to SCBU instead, eventually ending up in transitional care with me. Just a few short weeks after this, the nation was hit with a lockdown, meaning (as much as my parents were desperate to be able to provide physical help for me), I was alone. Just me. And that feeling that came over me and still does from time to time, hit me like a ton of bricks.

How am I ever going to do this on my own? All of the night feeds, every nappy change, remembering which consultant was going to call that day, the virtual baby classes, having emergency dashes to the hospital when she was poorly through lockdow, and remembering to feed myself too. It's been a challenging year for all, with a global pandemic, and trying to raise a baby through lockdown on my own has been extremely tough.

But it's also been the best year of my life, for exactly those reasons above. I did it! I managed to do all of those things and more! I've conquered a lot of worries, my whole perspective on life has been turned on its head. I used to think I was very open minded and aware of the big wide world, but my goodness how that has changed since Ada-Grace was born. She has opened up a completely different door for me. I've made lots of new friends from all around the world, I've raised money for charity, I've actively backed campaigns I truly believe in, I've honestly found myself and who I am meant to be.

And it's all because of this brilliant, one in a million, extra sassy, extra loving and extraordinary little human. A single parent will probably doubt their abilities often but to see how well Ada-Grace is doing, is more than enough to keep me going every single day. Spending every single moment with Ada-Grace has been wonderful. I've soaked up every moment of those little milestones, from her first smile and laugh, the first time she rolled over, sat up and the first time she clapped. And even in those moments of despair and worry, I've never truly been alone because we have the most amazing family around us who continue to be our biggest cheerleaders. She has truly taught me more than I can ever teach her. She is the best thing I never knew I needed…and I wouldn't change a thing!

A Sister’s Story

Sisters: Elodie and Clara by Mum Ginette

Elodie lights up all our lives and her big sister Clara is her biggest fan and cheerleader and fiercest defender.

There is only 18 months between them and although sometimes it feels a lot more, they have a fantastic bond. Of course, they fight like any siblings, but they are really protective of each other.

Clara was so excited to become a sister but I was worried she would struggle with the adjustment of having a sister with Down syndrome. We need not have worried though.

Learning sign language so she could talk and play with her, holding her hand and entertaining her when she had regular blood tests and even now helping her get dressed or make her breakfast, Clara does it all without question.

Meanwhile, Elodie utterly idolises her big sister and wants to do everything she does without even questioning if she is able to or not (her motto is “I can do this” or “try it”).

Elodie has incredible tenacity and determination that has served her well so far and this also inspires her sister to try her hardest too.

Clara said the best thing about Elodie was “her cute smile and giggles” while Elodie said she “Loves Clara to the moon and back” and her favourite thing to do with Clara is jump on the trampoline.

I am so proud of both of them for how they have handled everything big or small and how they look out for each other.

A Sibling Story

By Selah, sister to Simeon.

My name is Selah and I'm 12 years old. I have a brother called Simeon who has something extra special about him; he has Down syndrome. I remember waking up one morning when I was 5 years old and coming downstairs to hear that my parents were at the hospital and my little brother was coming. When me and my other brother, Jonas first laid eyes on him I'm pretty sure we knew at that moment that we were going to love him with all of our hearts.

Skipping forward to the present, we share the interest of performing. He absolutely loves watching my shows over and over. We have some on DVD and he's memorised it all! He's my biggest fan! He watches CBeebies pantos and acts it all out for us even at the most random of times. We also enjoy putting on performances for the family.

To our family, he seems just like any other young boy. Correction, even better! He does sometimes struggle more with learning things other kids may find easier but he is good at finding ways to overcome those difficulties. However, with some things he's a lot better than kids his age like social skills. Although he didn't learn to walk, talk, etc. quite as quickly as his peers, he was able to catch up.

When he was younger and got really poorly, I didn't understand what it was like. Now that I've experienced being quite ill and in hospital… quite a few times, I know how scary it must have been especially at that age. It broke my heart when I heard him waking up and crying in the night thinking about how awful that must have been. If that happened again, I know I would do anything I could to help him.

If I had the option to get rid of him having Down syndrome, I wouldn't. I think that's what makes him so special and unique even if it's hard sometimes. If someone said I'm sorry about him having Down syndrome, I would say exactly that. Life is never going to be easy and I wouldn't change a thing about him.

Whenever me or Jonas are upset, he comes up to us and asks what's wrong then cuddles us. He's caring, funny, loyal, friendly and just brings everyone around him so much joy. I can always count on him to be there for me. He is my best friend; I would do anything for him. He is one of the best things in my life and always will be.

My Family Story

By Rachel Murray

I live in Edinburgh with my mum and dad. I’ve got three siblings who care about me a lot. I am the youngest in the family. I miss my extended family who live in Dundee and Glasgow. I like football and when they play, I go to watch my big brother’s football team. I’m his top supporter! My big sister is lovely and she hosted a 21st birthday sleepover. I am lucky to have a sister, she’s the oldest.

I enjoy spending time with her now that I am older. I didn't always appreciate her when I was younger. My oldest brother has moved out but I like to speak to him on FaceTime, he is funny and he likes football too and we have that in common.

I’m close in age to my other brother and he even wanted to share a room with me when we were younger. I liked that he was still in high school when I started there and he and his friends looked after me in my first year just before they left school. Now we like the same football team and we sing football songs in the car. His friends still look after me and help me. I am glad to have all of my siblings because there are more close people in my life.

My dad goes out to work and he is my favourite, if I'm honest, and recently we’ve started having movie nights at home on Saturday with mum.

My mum works on campaigning and she is very good at organising in the home. We go shopping together and events together. She is a talented mum. My family is really good to me and we spend time together, we still go on holiday and we laugh together and have fun. I love my family; they are good to me and have supported me throughout my life.

We hope you have enjoyed these stories from our Wouldn't Change A thing families. For more about Wouldn't Change A Thing please visit our website:

www.wouldntchangeathing.org

On our website you will find Blogs, Ambassadors, Directory for other useful organisations and much, much more.

To follow our social media platforms:

@Wouldntchangeathingdotorg

@Wcatcharity_official

@Wouldntchangea1

@wcat_official