

# Down's syndrome and Autism – Matt's Story

By his mum, Helen Coppins



My son Matt was born in June 2003. We weren't aware that he would have Down's syndrome before he was born and went through the usual feelings of grief and shock that most new parents feel when they first get the diagnosis. Matt was diagnosed with AVSD and required heart surgery at 6 months old, which was hard for us all but he bounced back quickly and continued to progress.

By the time Matt was 18 months old, I had grown hopelessly in love with him and he was a joy to have in our household. He loved playing games with his older sister Rachael and was a happy, sociable and loving little boy. Matt amazed us with how quick he was to learn new things like Makaton signing and walking at this age, which he loved to show off to us all. We didn't see the Down's syndrome, we just saw Matt and he continued to grow and develop into a gorgeous little boy. I made it my duty to show him off to the world!

By the age of 2½, Matt had learned over 200 signs and had 30 spoken words, he loved to communicate and

share things with me and others. He was toilet trained and rarely had an accident. He was loving and gentle with his baby sister Hannah, enjoyed being kissed and cuddled, loved to sing and was animated and cheeky. At this point we thought that there was no reason why he wouldn't learn to read and write, make long-lasting friendships, get a job, get married and live independently. I was looking forward to a bright and happy future with my amazing little boy, but life is never that simple.

Around the age of 2½ – 3 years, Matt began to lose interest in toys, and in people. He became fixated with holes in things and after a while wouldn't play with toys at all. All he wanted to do was watch The Wiggles on TV. We noticed he was becoming withdrawn, but put this down to the arrival of Hannah a few months previously and his needing to adjust to that. But his fixation with holes continued. He then became interested in anything that would spin and spent much of his time spinning plates and other objects and hearing them clatter as they dropped to the floor. At the same time, Matt lost many of his signs and within 6 months had just 10 signs left and no spoken words, and soon after no signs at all. Matt also stopped giving hugs, lost all interest in people, stopped giving eye contact and withdrew into his own little world. Matt found new places too much to cope with, loud noises or crowded

places just overwhelmed him and he would throw himself onto the ground screaming, hitting himself or biting things.

It was hell. There was nothing we could do to stop the changes in Matt and it was absolutely devastating. I couldn't understand what was going on, although I had my suspicions, Andy and I, immediately thought 'Autism' (as it runs in my family) but didn't think it could just come on like that. Our Paediatrician told us that Matt couldn't be autistic as he was doing too well.

Watching my child regress from a happy little boy to the little guy we were left with was heartbreaking. Watching him in the corner spinning in circles and looking at his hand, isolated from the rest of us, it was hard to believe that just a few months ago he was a year ahead in his social development and such an able little boy. Losing his signs and being unable to tell us what he wanted or what was bothering him made him, and us, frustrated. It broke my heart when he hurt himself or was feeling sad and I tried to cuddle him, he would push me away and go and find a corner where he could stimulate or spin until he felt better.

Matt no longer acknowledged us, I could leave him alone for ages and he wouldn't notice I'd gone – he didn't care. And it really, really hurt when he

stopped calling me Mummy. When he started nursery school three years ago all I wanted was for him to wave at me through the window like ALL the other kids, but he never did and still hasn't to this day.

The only way I can describe how I felt around this time was as if my child had died, and as horrible as it sounds, sometimes I wished he had. I wanted the old Matt and was left with a child who barely noticed me, couldn't respond and whose favourite pastime was looking at his hand. Along with that, I became this person who everybody felt sorry for and that was a very hard adjustment as before I'd been the person who everyone came to for advice. I was the mum who new parents were introduced to, with Matt, to show them that Down's syndrome isn't the end of the world and actually my little boy is a bit of a superstar!

At this point we were involved in setting up the Notts Down's Syndrome Support Group, seeing Matt with all the other children with Down's syndrome and he was so different, he couldn't cope with all the people or the noise and just hated being there. Rachael was really missing her brother and couldn't understand why he didn't want to play with her or talk and sign with her anymore. Seeing her confusion and sadness made my pain even worse.

Accepting this new Matt was really, really hard. I was in love with the old Matt and didn't want to have to accept this new version. I had to abandon my old hopes and dreams of Matt getting

married, going to college and living independently. Like before when we were given the diagnosis of Down's syndrome, Andy and I had to grieve. I had to grieve the son I'd lost, only this time it was so much harder.

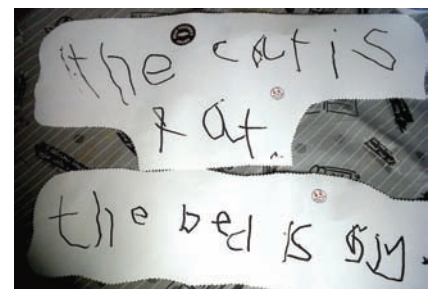
I desperately wanted my little boy back and would have done anything to get him back, but nothing was going to change it.

We researched the dual diagnosis of Down's syndrome and Autism on the internet, learning that most children with autism present autistic traits from an early age. We read that a second group of children are usually older, experience a dramatic loss in their acquisitions and use of language and social skills. It described Matt perfectly and at 3½ he was diagnosed with Autism.

Matt is now 6 years old and has the most amazing smile! He has no speech, he just kind of growls and grunts, but in the past few months he has started to sign – just 4 or 5 signs but it is so good to see him communicating again. He is never still and always on the move. He can use PECS but doesn't often have the inclination to do so. He loves noisy toys and after a while when he's bored with them, he throws them down the stairs to hear them make a loud bang! Matt will sit for hours on a swing going back and forth and this really seems to calm him down. Or he combines both activities, swinging and playing with his noisy toys together. I used to wish he'd play with different toys and be more creative but he

won't and his noisy, flashy light toys have been really helpful academically with learning numbers and letters, so that has to be a good thing.

On the positive side, Matt is doing really well at his mainstream school. The other children love him, even though he doesn't really interact with them and he has many friends. We realised that Matt was still very able academically, during the past two years he has been much more included in class and it has paid off. Matt knows his numbers to 100, can add and subtract and can count in 2's and 10's. He knows and reads all his 300 first high frequency words and is low average at reading in his class. He can spell words, not just CVC words but also the more obscure 'Umbrella', 'Orange' and 'Monkey' (courtesy of his noisy flashy toys!). Matt can type using a computer keyboard and loves playing games with the mouse. He was assessed and came out as scoring just under the level 2 that a typical child his age should be achieving.



Matt will now play with and hug his sisters, although always on his terms. We have taught him to give kisses again and although it's not spontaneous and he doesn't understand what



emotion a kiss conveys, the fact that he will do it is special to us. There are also negatives; toileting is on a timed basis because he doesn't tell us when he needs it; when he gets frustrated he hits himself really hard on the head or face or smacks his head on the wall or a chair – seeming to need the stimulation that this provides.

Matt has a very erratic sleep pattern; he'll go through phases of sleeping through the night for weeks, followed by weeks when he's awake for hours on end in the middle of the night. Melatonin might help but we can't get it down him! He has to be locked in his room with a high safety gate. Chewing his clothes cost us a fortune until we discovered 'bandana bibs' which Matt can chew to his hearts content and still look pretty cool!

Matt has no sense of danger and is king of the 'flop and drop' so walking anywhere is hard but we have a buggy for him if necessary. He still hates loud noises and gets so stressed by them that he wets himself, screams and head-bangs to make himself feel

better. Going out as a family isn't easy and we often have to do things without him, or accept that one of us will have to take him out or go home early with him. However, I'm a firm believer in getting him used to things and not letting Matt's autism dictate all our lives. A year ago I took Matt to a kids club I worked at, and church, and he hated it and would scream, hit himself, wet himself and throw himself on the floor before sitting shaking by the door waiting for the first opportunity to escape. People told me I was cruel and I did find it hard watching him going through such angst but I persisted and over time, Matt adjusted and those are now two of his favourite activities.

Matt has a great support worker through direct payments which gives us time to do things with his sisters. Matt is not fixed by routine and although he has some things he insists on doing his way, he will happily go from one activity to the next and not care if his routine is changed.

Matt is a nightmare eater and has a very restricted diet after recently

cutting out pizza, cucumber and sandwiches (which we used to put in his lunch box every day) he basically eats chips, beans, toast, fromage frais and skips. However, he saw a dietician who analysed his diet and said he was pretty much getting all the nutrients he needs – so we are happy to let him carry on and not try and battle to get him to eat new foods!

Having Matt as he is now, has humbled me and enabled me to understand better the problems other people face. Having Matt has taught me to serve without asking for anything in return. I have no option, he is my son. In loving him, I am able to love so much more profoundly and it's not about giving to receive, as Matt, most of the time, can't. My heart has softened and been humbled. I am much more willing to give, and to understand, and that has to be a good thing.

Autism isn't the end of the world but I can't say I like it!

The full version of Matt's story is on our website [www.downs-syndrome.org.uk/news-and-media/your-stories](http://www.downs-syndrome.org.uk/news-and-media/your-stories)

