

Being Ethan's Mum

By Nicky Holmes



Our son is watching Peppa Pig in what appears to be Swedish on his iPad. Sometimes it is repetitive roller coasters and water slides on YouTube. For some reason it usually involves lots of movement or a foreign language. Today it started at 4am and so far has been quite a gentle experience. We have had a cacophony of rude awakenings. We are best friends with every hour of the day and night. We are always on high alert.

Ethan was born in 2006 by emergency C-section and was 4 weeks premature. My husband and I had not indulged in any of the tests offered us during my pregnancy and I had meant what I said about accepting any baby. The moment I looked at the back of his new born head, noticed how his ears were sitting, so small, the thickness of the back of his neck, the fact that his middle and ring fingers were conjoined on both hands...I knew instantly that our lives had changed fundamentally. The overwhelming emotion of having a baby and then just 'knowing' that something was different. I was sucked in to a bubble of love, for a child who was going to need so much more help than many others. That day a Lioness was born in my heart and has never left me. One that rises up in unashamed defence of her Pride in any moment required.

We were taken to recovery and a paediatrician was called. Ethan was taken to the other side of the room, prodded and poked and

blood samples were taken from his tiny cold feet as he screamed. The paediatrician muttered something to a nurse, then turned and said "I think he has Down's syndrome" and promptly left the room. That was it. That was how we were told.

It took five days for DNA tests to confirm Ethan had Trisomy 21. I knew that already and so did my husband who went home and researched for hours on the computer. My parents and in-laws were hopeful it wasn't the case. Great grandmothers offered their condolences. Some people surprised us with their comments of, "it's such a shame" when the news was confirmed.

Nine years later and Ethan has been through several operations and endless assessments.

It is wonderful that so many people with Down's syndrome are accepted and celebrated in society. There are more possibilities now than there were even just 20 years ago, but there is another side to the story. There are some people that have more than just Down's syndrome, who have a dual diagnosis of Autism and Down's syndrome, those that are not always understood and treated fairly. (For information see the side panel on page 35). Parents of these children and adults can often feel as we do, that we are stuck in No-Man's-Land.

We adore Ethan and what I describe here is an open and honest account of our family experience.

As I write this, it has so far been impossible to get a dual diagnosis of Autism and Down's syndrome (ASC/DS). We have had to fight every system that we have been involved with – education, health, social services – to try and gain the help Ethan has needed – the support that we have cried out for as a family. The apparent difficulty we face, we are told, is that Ethan is not consistent across environments in his behaviour. Refusal for a dual diagnosis is that he also makes eye contact albeit strangely and can be sociable. The other recurring factor

always is "how much it costs". Ethan, our beautiful and challenging 9-year-old boy who has Down's syndrome (and something a bit extra, as yet undiagnosed) is often spooked at sudden, unknown noises out in public. I have lost count of the shopping experiences which have been interrupted because Ethan has been disturbed by a noise and people have just stepped over him or turned away as he is overwhelmed. We have ear defenders for him, in his bag, the car and at home, as well as a set for school. We have abandoned trips out, train journeys etc.

We've experienced endless sleepless nights, feeling isolated, wanting to understand our son's distress. We're often up for hours whilst he grinds his teeth, or wanders around the house unable to sleep, or empties his wardrobe so he can climb inside and retreat behind closed doors. There is the endless packing and unpacking of bags with toys and the flapping and rocking while he watches television. I try not to show it, but smeared faeces still surprises and shocks me. It can appear anywhere in the house or on Ethan. Ironically, he hates washing and gags and chokes when using soap unless it is absolutely on his terms. His school, with our permission, shower and wash his hair at school, because he can flatly refuse at home for a couple of weeks at a time. His new teacher is the best he has ever had and offered to help us out.

I'm not always able to finish a sentence because he cannot stand other people talking. I get thumped, punched, spat on and screamed at. As his mother, I bear the brunt of Ethan's behaviour, but it affects all of us. It is heartbreaking to see our six year old daughter, Ethan's only sibling, at times, terrified of his unpredictability.

Outsiders, however, only see what they want to see, the funny boy who likes to be the centre of attention.

The truth is we love Ethan with a passion that is hard to explain and that is the reason we have managed

to keep going for so long. We are fiercely protective of both of our children, but also know that we need more support.

At the time of writing we are still refused acknowledgement of our son's complex needs by our local authority in relation to gaining a relevant support package which will enable the sustainability of our family in the long term. It has been documented that he has autistic traits but we are denied an autism diagnosis. We have been asked countless times what difference it will make gaining a dual diagnosis. We use a care agency who have assessed that Ethan is a 2:1 case and yet the local authority will not acknowledge this and tells us in one of many assessments, that he is not classed as a child with complex needs. Yet Ethan is in a special school, placed by the local authority, for children with severe and complex needs.

We have recently been thrown a lifeline. The support we receive from the DSA has been literally that; a life line. It is wonderful that the DSA exists. I am personally very grateful to Stuart Mills, who has sent countless emails and spent so much time fighting our corner. In April last year, we also enlisted the help of a solicitor.

Outsiders, and quite often close family, still don't really 'get it' – the nitty gritty of everyday life with Ethan. "That's just kids" we often get told. We have many loving relatives, who have helped us out many times, especially financially, without whom we could not have continued, but there is a nagging isolation that goes with the territory, that unless you have lived it, you cannot necessarily comprehend.

Since Ethan's birth, we have had three family holidays in total. For the first we managed to gain some charity funding to help with the costs and so could employ a carer to come with us. We found a house that miraculously had a 'soft play' room. Ethan didn't sleep. The second was a disastrous caravan holiday which lasted three days out of seven, and divorce papers were nearly filed. Ethan didn't sleep. He was obsessed with the shower nearly flooding the bathroom and repeatedly opened and closed every door.

The third trip was equally exhausting, but more successful. It was funded by the wonderful Cotswold Down's Syndrome support group in Cheltenham led by Jenny King. The group arrange for families to go on holiday to the amazing Calvert Trust on Exmoor. They have several centres around the country and I highly recommend them as they are fearless in how they support people with disabilities to achieve.

The trip was still stressful, but Ethan gained some experiences we never would have attempted otherwise. The most memorable, abseiling attached to Daddy! And Ethan did sleep some of the time because he was so exhausted from the outward bound activities!

In the past I was told by a family support worker, to lower my expectations for Ethan and his life "Poor little scrappit" she said, "he will be able to push trolleys at Tesco I expect". To say my blood boiled would be an understatement. Part of our job as Ethan's parents is to be detectives and unpick his distress. Maybe that's why our surname is Holmes. We often joked when Ethan was in the womb, his name would be 'Sherlock'.

There is an endless list of professionals involved regularly in all aspects of Ethan's life. There are second opinions, specialist hospitals, endless communications back and forth, so much so it is a full time job 'administrating' Ethan. We will continue to seek answers, fairness and understanding for Ethan. To gain the support we all need to keep going.

So spare a thought for the stressed parent you see at the dentist or in the supermarket; for the child who is having a meltdown trying to climb up a mannequin in a shop window. They are not naughty children or bad parents. Sometimes the world is just an overwhelming place for some of us to be and empathy goes a long way.

And to all of you reading this that recognise aspects of your own lives, I hope it gives you courage to carry on in the knowledge that you are truly not alone.

Children and young people with challenging behaviour

Most children with Down's syndrome display behaviours that are common for all children during the course of their development. However, a small proportion display behaviours that have a more significant impact on the individuals concerned as well as on their families and friends who care for them, described as 'challenging behaviour'.

Down's syndrome and autism spectrum condition – what do we know?

ASC is more common in children who have Down's syndrome than it is for children who do not have Down's syndrome.

The profile of autism is not the same as it is for children who do not have Down's syndrome, it is 'atypical'. Children with Down's syndrome and ASC are less likely to show impairments in aspects of non-verbal communication including use of gesture, imitation or imitative social play. They are more likely to show impairments in particular aspects of language and to have more compulsions or ritual behaviours.

As a group, children who have Down's syndrome and ASC show more emotional symptoms and have significantly greater behavioural difficulties than children with Down's syndrome who do not have ASC, although some children who have ASC do not display challenging behaviour. When an individual's needs are understood and conditions created to meet those needs, challenging behaviour is less likely.

We also know that early detection is essential for provision of appropriate interventions, e.g. for improving behaviour, language and social communication.

The DSA is working to raise awareness and knowledge about dual diagnosis with ASC and to improve support services for individuals, their families, teachers and carers. Researchers are working to better understand the presentation of ASC and Down's syndrome and how to use screening tools.

All families should have the services they need to be able to provide care, support and interventions that can help whether or not the individual has an additional diagnosis.

To find out more about how we can help with information, individual consultations or training please send an email to info@downs-syndrome.org.uk.

See the Dual Diagnosis section of our website:

www.downs-syndrome.org.uk – For Families and Carers – Dual Diagnosis