

Parenting a child with Autism...the good, the bad and the just plain horrendously ugly truth.

When I was asked to write what it was like to have a child with autism, I thought about all of the metaphors that I could use to describe the emotional upheaval and drama of having a child like my son. Phrases like “roller coaster ride”, “never boring” (read “never quiet and sedate”) and “demanding and challenging like an epic journey” sprung to mind at first but nothing I could think of did it any justice.

So, instead, I’ll just get straight to the point; it is **very difficult** but I don’t know any other way of life and it is not like I have a *choice* in the matter; so my husband, my daughter and myself just “get on with it” and learn everyday to live our lives around autism and it’s insidious effects. I think the piece of prose by E. Kingsley entitled “Welcome to Holland” sums it up far better than I ever could, so I have included it with my piece for publication.

WELCOME TO HOLLAND

By Emily Perl Kingsley.

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

I won't bore you with the long, drawn out saga of my son's diagnosis, suffice it to say that no-one knew what was "wrong" until he was 5 years old. This is because my child has **Asperger's Syndrome** which is a less severe form of autism than the one effecting Dustin Hoffman's character in the "Rainman" movie, for instance, but it still effects every aspect of my son's life.

The Bad

Over-stimulation.

Asperger's Syndrome means that things that everyone else can filter with their brains such as background noise and movement, my son can't and therefore he gets distracted or distressed by noises, lights and other things such as itchy clothes, smells or even crooked pictures.

Noise is the biggest problem for my son, as he appears to have what I call "supersonic" hearing. He watches television with the sound turned down to 9 (out of 100 on the volume scale). He can hear ambulances and thunder miles away. He hates loud noises and will walk around with his fingers in his ears at shopping centers and near busy roads. My husband cannot take him to the football because the siren "hurts" my son.

I know this is because the nerves in his brain cannot process all the information that he is receiving in the same way ours does. But it is a bit hard to explain neurology to the local shopkeeper who suddenly has an 80kg teenager throwing a tantrum on the floor of his store because he turned on a noisy air conditioner!!

In the classroom, this means that my son gets very agitated whenever there is a science prac involving gas or flames or anything that could go "boom!" If it's a noisy drama class, he will crawl under a table to try and shield his brain from the onslaught of loud teenage voices and laughter. He cannot do food or wood technology because he would run screaming from the sound of lathes or from the possibility of the ovens exploding. So if we were to imagine it, I guess its like walking around with the volume turned up to 50 –all the time – with no respite – even when you sleep!

Routine

People with Asperger's are so confused by life that they find a great deal of **comfort** in having a routine and sticking to it...*literally, at all costs, on pain of death!*

If anything happens to upset this routine, stand back as all **hell** is going to break loose.

This is particularly true if I, as a parent, tell my son that we *will* do something and, for some unforeseen reason, we can't do it. A "normal" child will accept that, for example, we can't get an ice-cream on the way home because I don't have any money because I had to buy toilet paper or whatever. My son will NOT accept this – having tuned his mind to how the day will unfold, he cannot fathom that we are NOT having ice-cream and so will have yet another tantrum in his efforts to bring the day *back on track*.

Therefore, I as a parent, always have a Plan A, B, C to Z, just in case things may go off track – it is less hassle that way!

Lack of Social Skills

Although everyone always says they want other people to be honest – this is not true. People want others to be honest as long as it doesn't hurt their feelings and please say it nicely. The child with Asperger's Syndrome *will tell it like it is*, or at least how they see it. This creates a wealth of difficulties, especially for the teenager trying to make friends and fit in. "You look fat in that dress." Will not endear any child to one of their peers and so my son does not receive any text messages or e-mails and is never invited to parties or to other kids' houses to play.

I could go on and on about the bad but these three sum it up nicely.

The Good

Honesty

There is a simplicity to my son that only comes when you spend some time with him. He calls "a spade a spade" when he looks at life and this can be quite refreshing in a world where everyone treads carefully around others. He is actually quite astute in breaking down the heart of any arguments or problems as he is not encumbered by any emotional baggage.

Often his observations are hilarious and it is only our sense of humour that keeps us going. His connections between things in the world are often quite off center. For example: Passing over the Batman Bridge in Tasmania (named after John Batman) we asked my son if he knew who this bridge was named after. In his ability to link certain contexts together, my son replied, in all seriousness, "I know, it's named after Adam West!" My husband had to pull the car over, he was laughing so hard!

Loving

I am extremely lucky in that my child has Asperger's Syndrome instead of full blown autism as I still get lots of "I love you Mumma"s and kisses and cuddles. Kids with fully blown autism will kick you if you try to cuddle them. I could not think of anything worse than as a mother, trying to show your child affection, and having them reject you. It would break my heart. So I am grateful for my bear hugs and my sloppy kisses –even the bear hugs I get now from my huge teenager!

Phenomenal Memory

My son has an amazing recall. He can remember what he ate at a certain pie shop we visited when he was 18 months old. (That was more than 12 years

ago!) He can recite verbatim conversations that have occurred and this makes his verbal skills outstanding. I admit to often using him as a walking diary – what day did Mum say she would meet Auntie ? and he can recite the date and time without any problem.

The Horrendously Ugly

“Inappropriate Behaviour”

Today is a prime example. I write this knowing that it is a Thursday and once again, my son has gone beserk at school. He has ripped up his work, tried to heave over an entire locker bay and then thrown dirt and spat at teachers. He has tried to kill himself yet again, when he has realized what he has done in a fit of blind anger and now comes home to me with bruises on his legs and neck and circles under his eyes from crying.

I, as his mother, feel helpless that I cannot do anything to ease his burden. For me, the **choice** between right and wrong is simple – I will always choose right because it is the best, easiest and simplest **choice** to make. My son, on the other hand, has no **choice** – his warped brain, over stimulated by who-knows- what around him, has chosen to react in the **WORST** possible fashion and so he must suffer the consequences – the guilt at what he has done and the pain that he has caused his aides and teachers and his parents. It is such a huge burden for a child to bear. Sometimes I wish that he was **MORE** autistic so he wouldn't be so **AWARE** of what happens when he “loses it” and the consequences of his actions.

So that is basically it! A glimpse into the life of our family which revolves around **Asperger's Syndrome** and its effects! Hopefully, the next time you see a similar kid to my son acting strange in a supermarket or car park, (or even as you pick up your own children from school), you might remember that he could be from “Holland” and you will then thank the stars that your own children are from “Italy” instead.