When Kathryn and Benison contacted me for input on this revised version of the AHB, I was honored and enthusiastic to share the last 5 years of my journey and the journeys' of those who have bestowed enormous trust in my professional and personal experience. I reread my original chapter and I wept for the mother who had survived that part of the journey. The ache in my heart still remains and the tears still flow.

In all honesty, the last 5 years have been a reprieve from what I considered to be a "life sentence" in those earlier days. Today my son is nearly 13. He is an absolute legend in my eyes. Weird – yes. Dodgy (Nic's word) – yes. Quirky – absolutely. He is a sweet charming young man with a gentle nature, who is more articulate than I. He is no longer obsessed with Star Wars - history and gruesome facts have replaced that, maybe this will lead to a career in teaching, one never knows. Presently he attends a Montessori school and is transitioning to a nurturing high school, in Sydney, next year. They have an excellent history and languages programme as well as other activities in the curriculum that seem to suit him. He chose the school.

It is a smaller high school; slightly non-traditional in its methods and outlook and full of teenagers who are allowed and actively encouraged to express themselves in their own unique and individual way. Although we have kept up weekly speech therapy (only during term time) we have replaced his other therapies with more "user friendly" versions. He is a provisional black belt in a martial art, a not very budding tennis player, an awkward surfer and a mean teller of jokes; many of them cause my male friends to mutter, "boom boom" upon delivery! He feels pain of his own and empathises with the pain of others on occasion. He is polite, well mannered, cheeky and has learnt to lie (the first time I caught him out I cracked open a bottle of French champagne to celebrate). A far cry from my metaphor of ASD being a black hole and giving me nothing in return. My disclaimer here is that he has not yet attended this school. I would always quip that my next nervous breakdown was scheduled for high school. I don't feel like that any more.

I have heard myself say that my son's ASD cost me part of my soul, my heart and my life force. I believe it did. Was it worth it? HELL YEAH! Without his gift to me I would not have been blessed to witness the darker side of life (and without that gift we make for very boring dinner guests). I would not have learnt what it means to want to hide under the doona every morning, but be forced to get up regardless and keep moving forward; shed a tear at a sad movie in public; gasp in awe of a random act of kindness or beauty, be comfortable to stare in the eyes of a child in a wheelchair and stoop to talk to them when no one else did. In short, my world and consciousness has expanded as a consequence of raising my sweet sons and has led me down paths I would never have believed possible. I have learnt to be "self ish"; i.e. put myself first, have more "self" most of the time; which in turn has been for the good of us all. In short, I have given up guilt for a living, I have a life, feel passion for it again and can see a brighter future. It doesn't look like how I planned it, but does it ever?....

"Is life getting back to "normal"? It's our kind of normal"

When clients first come to see me they often enquire about my son, my life, how do I manage to work? Do I socialize etc? I feel they are desperately seeking reassurance that there is life after a diagnosis of ASD. One of my secret ingredients to survival has always been my sense of humour and ability to laugh at myself and uncomfortable situations. Another vital component is other parents in the "same boat". I am blessed with 3 other families to socialize and holiday with. We laugh together at our kid's antics; celebrate their wins; commiserate their losses; cry when we need to. We have been known to pass the wine at dinner when one of our kids "loses" it in public! Long gone are the shame, anxiety and panic of those episodes; it is replaced with gentle coercion, smiles, soothing and time outs (for us and the kids!). The embarrassment I used to suffer as a consequence of my son's behaviour has faded. My biggest dilemma now is his unfailing honesty in the most inappropriate of situations! Thankfully I have a great sense of seeing the humourous side whenever possible and I have developed a very thick skin, both are highly necessary for survival.

There are no hard and fast rules on rebuilding our lives after a diagnosis. I am constantly amazed and encouraged by the creativity and resilience of the parents and carers I meet, their survival techniques, their compassion for themselves and their caring of others. They all share an unfailing need for an easier life, yet their tenacity to forge ahead and unwillingness to accept a prison sentence for their child, themselves and their extended family is exemplary.

Having worked with parents of ASD kids and a broad spectrum of other disabilities I have been taught about the many commonalities we have. Primarily guilt, often shame, a struggle for acceptance, grief and loss, exhaustion, despair, fear of the future, denial, anxiety and a complete loss of control and "normality" as we once knew it.

I have come to believe that the journey of healing for most carers starts when their child enters education. When school begins, after the initial hard work of transition is managed, we can feel a sense of weight lifting from our shoulders. A feeling of "shared care or responsibility" is then possible. As our children mature, their self-care skills tend to increase. Hopefully, their language and socialisiation too. If we can find it in our beings to relinquish a level of control and "over protectiveness" we have come to adopt, a faith in humanity can redevelop and we can breathe again. This has many variables of course. Finding the right educational environment for our child can be tricky and take a few attempts. A good and sympathetic teacher (that our child likes!) is essential, but when we win we can begin to relax. Our children are often more resilient than we give them credit for - as are we. I tell my clients to go back to bed for 6 months if at all possible, just so they can recover from the early years. Self-care at this time is essential. It is when most parents enter therapy. They are no longer as consumed with early intervention; and now encounter a stage where they have more time on their hands, which can exacerbate their grief once again. Rediscovering their interests, relationships, fun, and other children becomes essential.

Letting go and trusting

As in the life of any child, we experience a need to nurture, protect, soothe and sometimes a strong desire to wrap our kids in cotton wool to protect them from the "cruel world". A world for them of struggling to fit in, teasing and in some cases bullying and a testing of skills and resilience lies ahead. Anyone who has raised teenagers will identify with how much of a "letting go" experience that period of parenthood can be. Allowing your child to step out into the world with less of your protection. Having to trust our parenting thus far to enable them to make good judgements, asses dangerous situations, say NO when peers push them to do things they feel uncomfortable doing etc. We send them off into their maturing world of self-reliance with trepidation. An invisible body suit that protects all negativity, would be undoubtedly a best seller for most parents.

Having an ASD child going off to school is like this too, except we have to learn these skills ASAP. Relinquishing control and trusting they will survive when their skills are diminished is a very tough call. I remember the principal at my son's school sidling up to me on his first day to check I was ok, rather than him!

For our own survival this is essential and finding the balance of involvement and detachment is really tough. When we over focus on our special needs child we under focus on their siblings…

SIBLINGS

From my personal experience, my eldest son went through many difficult times during his younger brother's early years and therapy. He was sometimes ashamed of his brother's behaviour, bewildered by it, enraged and often deeply saddened at the loss of the little brother he had always wanted. He had longed for someone to kick a soccer ball with and rumble around on the bed for a wrestle. They now do the latter in abundance, harmlessly, most of the time! However, soccer may never be a game that they will enjoy together though.

Over the years, I found many pep talks and explanations necessary over the years and for all my eldest son's faults, he really has been his brother's best protector, advocate and teacher, second to his father and me.

One evening I took him to a preview showing of The Black Balloon movie. We both watched in horror with tears cascading down our cheeks. I had already seen the movie to give myself space to honour my own feelings and check out whether it was suitable before I took my eldest son, who was 14 at the time. We sat in silence at dinner afterwards for about 20 minutes, both digesting the similarity to our lives. Later I asked him "so what did you think?" He replied "I have wanted to smash the playstation over his head many times"…. I was able to hear that, acknowledge those feelings in him and thank him from my heart for never having acted out that frustration.

In my search for peace and acceptance for my NT (neurotypical) son I found siblings camps and socializing with other kids who had ASD siblings a blessing. One time, my son returned from a camp, where he had been spoilt rotten, and he expressed his gratitude that his brother was not as much of a drain on him as some of the other kids he had met there.

Siblings of special needs children can over develop compassion, empathy and a greater social awareness for the needs of those less fortunate than them; I believe this can be a good quality in life. I had a phone call from my eldest son's school once congratulating me on his attentive behaviour of another special needs child in his year. The same term I also had a private conversation with a male teacher of his who let me in on some of my son's less orthodox means of ensuring 2 students with Asperger Syndrome were no longer bullied!

In my experience, sibling recovery is closely linked to our own. Maturity and peer acceptance are paramount, yet I have observed that if we, as parents, work on our anxiety and grief process, learn to accept our new lives and rebuild them to the best of our abilities then our children have permission to do the same. When we invite open and honest communication into our relationships, soothe our anxiety, share our time and resources as effectively and fairly as possible and provide good role modeling for our NT siblings, they will be fine. Else, commonly they will leave home at the earliest opportunity in order to have a life.

GUILT

This is insidious and a gift bestowed upon us in childhood, by religion, parents and family, and the moment we give birth or have our first child. It is for the most part a waste of emotion. On the flip side, it stops us from committing crimes; it supports us to be kinder to humanity and gets us out of bed to perform our daily tasks. When it consumes us, we are vulnerable, ridden with self loathing and can under function as a consequence.

Personally, I went to work in a women's drug and alcohol rehabilitation unit when my son started school. It was tough work, but a far cry from disability, a time out I sorely needed. I had an epiphany one day whilst holding a baby boy of approximately 10 weeks in my arms whilst he was waiting to receive his methadone dose, as his mother was addicted to heroine during her pregnancy. As his cries of pain due to the withdrawal of the drug wrenched at my heartstrings. I was left wondering about my role as a mother. His mother had experienced a traumatic and horror filled previous life before her drug addiction. She was doing her best; she was in treatment, the best place for them both. I went home from work that day and wept for half of the night. My tears were not only for his pain; they were for my pain too. The pain of the realization that I too, had been doing my best. My best was caring for my children, being there and present as often as I could be. Finding good therapy, good schools, good interests, providing a good and loving home and environment for my children as best I could during their early years. The realization that by working on my own anxiety, regaining my self esteem and a life was the best possible scenario for us all. I vowed NEVER to put myself through guilt again. It wasn't about his mother being a bad mummy; she was now in treatment. It was about me being a good mummy. I was the best mummy I could be given all the circumstances of our life. I could honestly say then, "I am doing my best".

The guilt of my son's diagnosis was eradicated after working with other parents of ASD children. There is no way we all did something the same at the same time during our pregnancy, or their infancy, that caused their ASD. Some journeys in life are just harder than others. Some things in life are just not fair. Sometimes there can be just bad luck…

SUPPORT

We cannot exist alone. This is why we mammals group ourselves.

My self care and work on my anxiety and grief has enabled me to reframe this entire experience. I am now aware of how resilient I am. I have survived! I now tackle life's other issues differently. Life, and its struggles are always going to happen. Our parents will die. We will lose jobs, friends, relationships, homes, money, and love…. With resilience we can cope with anything as we build new pathways in our brains that alerts us to previous traumas we have survived and can soothe us through the next major life event we will encounter. It requires work; often good therapy, feeling safe, self-soothing and self care skills and often an honest expression of our pain. We stop minimizing the tough parts of life for fear of lack of acceptance and we start the day meeting our needs before the needs of others. Like the analogy of the oxygen mask on the airplane, it is really a great metaphor for trauma in our lives:-

"If cabin pressure should change, panels above your seat will open revealing oxygen masks. Reach up and pull a mask towards you. Place it over your nose and mouth, and secure with the elastic band, that can be adjusted to ensure a snug fit. The plastic bag will not fully inflate, although oxygen is flowing. Secure your own mask first before helping others".

Life's pressures do change, we do have a lifeline. If we choose to reach out for it and grasp the lifeline, at first it may not seem to be working, but trust me, it does. Most importantly, fulfill your needs before the needs of others else you may not survive.

Another recovery routine for me is massage and therapies that soothe my nervous system. I don't know if I feel fully recovered from the stress of the early years, I believe I suffered a form of PTSD (Post Traumatic Stress Disorder) from my experience of ASD. It left me with anxiety and worries about the future. They are similar to ones I expressed in the last chapter, just the intensity has lessened and I have adjusted my expectations to suit our lives now.

My son has a piece of paper (diagnosis) that says he has autism spectrum disorder. He is now a delight to be around. This is only a small part of who he can be and reminds me to care for his additional needs and different learning style. The piece of paper is very useful for funding at school but that’s all it is useful for now. I hope and pray that he will find his way in the world, have a job, get married, live independently. I am not sure he will, but if I have anything to do with it he will certainly try.