

Through grief to self care....

How to look after yourself and your family...

By Justine Watson

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If you are reading this book, it is highly likely you have a child, close family member, pupil or friend with autism. You may be the parent and feel that this complex disorder consumes your entire life, nearly all of your energy, thinking time, resources, finances and emotional wellbeing. You may be a relative or friend, who is aware of the challenging nature of the disorder. You see the management of the child taking its toll on the family and have a desire to understand more about it and ways you may be able to help.

Although a diagnosis of ASD may feel like the end of life as you knew it, it need not be. There are ways to navigate the emotional as well as the practical maze of autism. The shock and grief will lessen and this will enable you to regain some measure of control in your life. Picking up this book is evidence that you are on your way; congratulations on taking the step. There are new skills you will be able to learn as you read on. You may surprise yourself at the talents you already have and the ones you will acquire along the way.

There will be good days and bad days, good weeks and bad weeks. Caring for a child with ASD may overwhelm you from time to time. Finding a balance in your life is the key. If everything is 'spent' in the first year, what will be left for the years to come?

Why do parents feel such a mess?

I saw autism as a 'black hole'. In the early days, it took everything I had and gave me nothing in return. I taught my son as much as possible and got little in return, very few smiles and cuddles just blank looks and appalling behaviour.

I remember feeling just one big mess after receiving the diagnosis. As the developmental paediatrician delivered the 'verdict' I felt as though my life

suddenly changed to slow motion. I felt removed, distant and numb, to the extent that the rest of the pediatrician's words left me feeling like I was the dog in the popular comic strip listening to a human and hearing only 'blah, blah, blah...'

This stranger had, in seconds, delivered me a life sentence — AUTISM . 'A life long condition with no cure,' was the description I read. I felt that my heart was being ripped out and stamped on. I was in shock.

My days and nights became a whirl of trawling the Internet, talking to other parents, reading ASD books and spending the little sleep time I could get dreaming about autism. This time did serve a purpose, education, which did help to temporarily soothe my anxiety.

The intensive early intervention path I chose took up every waking hour. I became a mini speech therapist, a Makaton trainer, a mini occupational therapist, an ASD researcher, a behavioural therapist and often a mini medic 24 hours a day. This didn't leave much time for me, time to consider how I felt. The anxiety that had been triggered inside me just kept building.

Questions would regularly race through my mind:

What about the future?

Will he ever talk?

Will we ever have cuddles?

Will he tell me he loves me?

Will he live independently — have a job — get married — have children?

Will he ever play soccer like his brother?

Will we ever get to know each other?

Will he ever care what I think or feel?

All these potential losses came crashing into my consciousness, exacerbated by the loss of the 'normal life' that was slipping away from me, rapidly, as I burned both rubber and cash consulting a variety of health professionals seeking much-needed support.

The anxiety I already carried was being triggered to levels well beyond my ability to cope. If I hadn't been in the counselling industry, I really don't know if I would have coped at all. I had the support of a therapist, some colleagues, and good friends at that time but the missing link for me was other parents in a similar situation, the other unseen heroes, all in the same boat as me.

Eventually, I found a couple of other mothers and they listened to me, soothed me and guided me through the maze of different therapies, treatments and professionals. In time, I would do the same for others and we all learned from each other. This has been an essential ingredient in my journey.

The intervention plan I put in place soothed my anxiety as well, as it enabled me to begin to feel some form of competence again. Everything I had been doing as a 'normal parent' wasn't working —it was just giving me a feeling of being useless and de-skilled! This pain lasted for 12 months or more, until my son started to make a little progress and I was able to see the fruits of my efforts, in the form of words and simple self-care skills.

My maternal instinct was to keep my son at home to 'protect' him from the world. It took my trusted speech therapist to convince me that this may not be the best course of action. I chose some care outside the home and some assistance in the home to give myself, other members of my family and importantly, my son, some balance. This was when I was able to start taking some time for me, and giving myself some thinking space for our future.

Once I started to take some time out, I began to think of myself as a counselling client. I thought about what I would be encouraging a client to do for themselves. What would someone need when they were walking into the unknown world of autism?

Firstly, I had to address the crippling anxiety and sadness I was trying to suppress. I began to be very firm with myself and banned myself from thinking about the future. I was not to think more than six months ahead in the beginning. This timeframe was allowed to grow, gradually, to thinking up to 12 months ahead. At the present time, with my son aged eight, my next nervous breakdown is booked in for commencement of high school! I allowed myself my tears and frustration, and gave myself permission to grieve, permission to be angry.

The process of grief can be likened to the care of a physical wound. After the accident/trauma we need to assess the damage, often whilst in shock. We know we will need to attend to our injury. We may have to pick out gravel or dirt from the wound. This hurts and takes time and care. We then apply an antiseptic, which causes pain again. We may then dress the wound and make attempts to protect it, this takes time and a lot of care. This may be a daily routine until a scab forms to protect the wound. The scab may be knocked off or it may crack and it hurts, again, we may have to go back to the antiseptic and daily care routine once again. With time and tender, loving care the skin grows back over the wound and it becomes a scar. The scar is a reminder of the wound and a reminder of how that area will never be the same again. Like a scar, grief takes time to heal and does so best with care and attention.

I was lost for ways to nurture myself. I had become isolated, having lost friendships whilst we were living under 'house arrest'. I had stopped all the fun things I used to do through lack of time, energy and cash. I had become obsessed with autism and a shadow of my former self. I simply had to regain some 'self'.

I had neglected my self-care. I was constantly anxious, exhausted, irritable, unable to 'switch off' and certainly not able to sit still and 'just be'. Here I was getting my son all the help in the world — what about me? I thought back to the things I used to love to do: going for walks, meeting friends in coffee shops, going shopping, dancing, watching movies, going to the gym, reading novels, enjoying sunshine, eating well and sleeping etc. I was just doing autism, 100%!

Once my son had a comprehensive program in place I forced myself to start to take better care of myself. I wrote a list of 'things that nurture me' on my kitchen wall and my mission was to complete at least one thing every day. This was, of course, excruciatingly painful in the beginning. I constantly felt I should have been doing more for my son and any time I took for myself was time taken away from him improving.

The guilt I experienced was something I had to overcome if I was to survive. My inner voice was also telling me that if I carried on in this way I was heading for some kind of a break down, as my new ASD-obsessed lifestyle was not sustainable for the long term.

My self-care actions were invaluable to my wellbeing. In my experience of facilitating support groups and working daily with parents of kids with ASD, I have found that once mum is willing to put herself first, family life changes. Happy mum = happy family.

I have seen tremendous transformation once grief, guilt and shame have been addressed professionally, within the safety of a trained professional's office. A weight gets lifted and parents feel as if they can breathe again.

Parents, especially mothers, usually arrive at counselling exhausted and desperate. Once they can grasp the concept and importance of self-care they often start to see a difference in family life, relatively quickly. And, importantly, they start to minimise some of the guilt they feel for taking time away from their child. It is not unusual to feel guilty when we first leave our child with anyone else, even if it is our child's immediate family. In order to survive autism, this is a skill we MUST learn and practice.

For some mothers, going back to work is one of the ways to bring normality back into their lives. I know it helped me to get my life in perspective and have something for myself outside of the home and family. It has crossed my mind, that if I hadn't been a parent of an ASD child I may not have had the opportunity to learn how to take care of myself emotionally and physically quite so well. I had to learn to give myself permission to relax and enjoy other activities. I now see the blessing in this, and have discovered the importance of allowing myself 'thinking' time, relaxation and fun! I needed to learn how to make myself happy, despite life's attempts to pull the carpet from under me. I learned how to appreciate the little things in life and not to take anything for granted. The kind of

stuff Oprah talks about that I just didn't connect with in the same way, until my life was turned upside down by this cruel disorder.

I feel that the parents of kids with ASD are highly susceptible to depression. We all suffer from lack of sleep, the exhaustion of the 24-hour care these children demand of us, and strain on our physical and mental health, and nervous system.

In addition, relationships with these children are often severely impaired: parents don't receive much in return for their efforts. Although we want to give unconditionally, we are human beings and we have a desire for reciprocity. We get emotional feedback in day-to-day relationships with others and with our typical children. But with children with ASD in the early days 'unrequited' love can be demoralising.

We all know children are hard work and usually, it's those 'special moments' that make the effort worthwhile:

- smiles and hugs — the 'I love you Mummy/Daddy'
- team sports
- reading to us
- music they play for us
- the thought of our future grandkids
- listening to their dreams for the future
- academic achievements

When we lack some or all of these moments, the task of parenting can feel thankless.

For example, when we have babies they consume all of our time, feeding them, settling them, nappy changing and staring at them! Within weeks all that hard work is rewarded with smiles and gurgles. With an ASD child in the formative years, the rewards, if we get them at all, are normal child behaviour (eg toilet training, feeding themselves) often accompanied with crying and resistance rather than with smiles. I always explain to parents of typical kids that all the skills your child learned by osmosis, I had to teach to mine.

Another reason we, as parents of ASD children, are under so much strain and susceptible to isolation that can lead to depression, is that our kids often look normal on the outside. If you spend any time with an ASD kid you will quickly observe that everything is not quite normal on the inside. When we attempt to shop in the supermarket and our child has a sensory meltdown people might glare at us and feel compelled to pass comment on what they consider our bad parenting skills! We are judged in public by people's ignorance, time after time. The lack of support in the community can be very isolating and diminish our own self-worth, and can lead to social isolation.

Does medication have a place?

Dealing with loss, grief and depression is debilitating and often means we don't function as well as we would like to. Some people have a resistance to medication for depression. Some are happy to embrace it. Others might overuse medication and other substances to keep their feelings at bay and not deal with life in general.

Any one of us may be vulnerable to the overwhelming impact of the grief of having a child with ASD, the loss of the 'normal' child and the loss of normal life. Although we may want to 'tough it out' or feel we shouldn't 'need' medication, anti-depressants may have a place in this journey if we find ourselves too overwhelmed and unable to cope.

Not everyone is born with the same amount of serotonin. Many of us are born with high levels (serotonin is a happy hormone in the brain) others are not. It is worth checking with a medical professional or your GP as medication in the short term, may improve YOUR situation,

How to take care of your relationships?

The current notion of 'family' embraces a variety of relationships and genders: two-parent families, one-parent families, same gender parents, grandparents, adoptive parents.

If you are a sole parent it is important to take on board the principles of taking care of important relationships in your life; the most important being the relationship with yourself. When you're giving to children with such high needs all the time, and there is no partner to give to you, you must give to yourself to even out the balance.

Many relationships suffer on this journey and some break down. I have seen a variety of coping mechanisms partners take on during the crisis of diagnosis. In order to understand this I explain to parents the things I learned in studying family therapy. It is believed that when we are in an ongoing love relationship we bring to the table, the bedroom, and our day-to-day lives, the thoughts and feelings of our forebears. Our family of origin, our childhood family, has imprinted many thoughts, feelings and beliefs on life and how it 'should' be.

So when a crisis, trauma, loss or tragedy occurs we revert back to how our family of origin would have dealt with it. Think back to a time when one of your primary carers experienced a trauma. Maybe they lost a parent, lost their job unexpectedly, got sick with a terminal illness, had to move cities or maybe countries. How did the family respond?

- Was there much communication?
- Were your fears, worries or tears addressed?

- Did you feel supported while the grown ups in your life fell apart?

How do we deal with the crisis of a child whose needs are so great, coupled with the loss of the anticipated 'normal' child we all expected? How do we handle the impact that has on the family and our relationship?

Most of us hang on for grim life, like 'white knuckling it' on the roller coaster, hoping and praying that when this gets better all will be well. But how do we minimise the collateral damage?

I teach parents to be detectives. Look at how your partner and their family of origin deal with trauma and have dealt with it in the past. This will give you insight into coping mechanisms.

- Has your partner just shut down and withdrawn?
- Are they constantly weepy and unable to focus on a task?
- Have they started to drink every day to cope?
- Are they putting in longer hours at the office to avoid coming home?

We all cope with trauma in different ways. Problems arise when the ways we choose to cope are driving a wedge in our relationship.

It is during any 'tough times' we discover the fabric of who we are and how we cope and the same about our partners, family members and friends. If your body was sick then you would go to a doctor. If your relationship is suffering wouldn't you go to a relationship doctor too?

For some of us this is a tough call. Admitting we are having relationship issues is hard to do. However, it is liberating when we do. If you were to break a bone you may have to do rehabilitation or physiotherapy plus a series of often painful exercises in order to facilitate the healing process. Relationship therapy is similar.

Exercises may include:

- how to listen and be heard effectively
- how to communicate your needs and have them met
- understanding each other's coping mechanisms in grief and trauma and the impact they may have
- reminders of what made you fall in love in the first place.

This is a tough process, but a good way to stay engaged with your partner and, importantly, to model good relationship values to your children.

Having a 'date night' is essential. A night out together every week (or fortnight) that is solely for your relationship is a way to reconnect and is vitally important for both parties. The time is not for discussions about autism or difficulties, it is to relate to your partner and remind yourselves that you are human beings as well as parents who take time out for each other because you matter. It's also really

important to have some fun, engage in activities you love and take turns to choose the agenda!

The golden rule is to keep in mind is that you both have a broken heart due to your child's autism. Everyone deals with a broken heart differently but how you react has nothing to do with how much you love your partner.

For me, our lives began to resemble our 'new normal' in the first year my son went to school. I am fully aware that this isn't everyone's story but at some stage, life has to regain a sense of 'normality'. I returned to work, and my other son was able to take on more enjoyable activities as well as receive more of my time. My ASD son improved and the school system shared some of what I had previously termed 'the burden'. Things became more 'normal' and bearable.

By normal I mean:

- base level needs are being met — everyone in the family is sleeping, eating well, exercising, resuming normal activities etc
- the financial resources are more evenly spread through family members — holidays and other activities are possible again
- Mum/Dad have resumed work (if they gave it up initially to cope with their child)
- respite is in place
- parents both have time out as individuals
- parents have time out together and time with other children
- siblings are receiving an equal share of time from the family
- the family becomes more accepting of the child's autism.

It may be easy to feel resentful hearing my story if you have a severely autistic child. You may feel the whole idea of getting to a stage where you felt you could implement some strategies for a 'better life' is very remote. You may be so comfortably numb in the 'hard life' that there is no longer light at the end of the tunnel. My heart goes out to you.

In my practice I have had parents of severely autistic kids who have, against all odds, completely changed their lives and the future of their family. They have had to make hard choices: some have moved home, involved a respite service in or out of the home, surrendered some control/care of their child. Ultimately their bravery has resulted in them changing their lives and they have started 'living' again. It is possible with support.

Another thing I learned on this journey is that you need to be comfortable with all the professionals you allow into your child's life and sometimes into your home. It is imperative to trust them professionally and feel that they will be able to provide the best care for your child. If you don't, you could waste a lot of time and money on a path that isn't right for you or your child. Developing that parental intuition or the 'all knowing voice inside' is crucial on this journey.

Summary

My life will never be the same as it was before autism.

Without autism, I would never have learned to be in awe at a spoken word. I may never have been able to see the wings on the backs of the children who passed the parcel for my son at parties. I too, may have judged those 'terrible' mothers in supermarkets whose 'horrible' children throw tantrums instead of speaking!

Without autism, I may not have had the honour to meet some of the most determined, courageous, tenacious superheroes (disguised as parents).

Today I have a more normal family. My son is weird. He does strange stuff, he's funny and quirky and has special gifts that other kids don't have. He is our gift. I still feel sad at certain times. I take care of my grief by knowing that at his birthday party and sometimes other kids' parties I may feel sad at the loss of the 'normal child' I didn't have. At the school Christmas concert I cry more than the other mums. That's normal. I take better care of myself at those times.

Two things I hold sacred now:

Look after me first, because if I don't, then who will look after my children when I cannot?

Autism is a marathon not a sprint.