WHEN AUTISM IS TEARING YOU APART

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A MOTHER'S RECOVERY GUIDE TO FINDING COURAGE, CONFIDENCE, CALM & COMPASSION

LIZ SMALLEY

When Autism Is Tearing You Apart

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This book is dedicated to my tribe - mothers of children with autism. Thank you for your many unnoticed efforts and unheralded sacrifices. Thank you for being brave and rising to the challenge that's harder than anyone else not in our tribe can ever imagine. Thanks to the hundreds of mothers who participated in my research.

Thanks to my husband for sharing the journey of raising our son who has autism and an intellectual disability.

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HOW TO USE THIS BOOK

I want to make reading and using this book as easy for you as I possibly can. I know you're busy! You may not want to read every single page I've written. That's perfectly OK with me.

To help you decide which parts of the book will be most helpful for you and worth your time, I've kept chapters short with several subheadings. I've given you a summary at the beginning of each chapter, so you can decide if that's the information you need right now, or if it can wait until later. Feel free to skip around as required to best meet your needs now.

I've used "him," "his," or "he" as pronouns when speaking about our children with autism for simplicity and because my experience is with a son.

You will find a reference list at the back of the book and a link to my recent research paper. You will also find a list of other recommended reading resources.

PART 1

Chapter 1

INTRODUCTION

How Is This Book Different Than Any Other Parenting Book About Autism?

You're going to hear about the trauma that those of us who are mothers of children with autism experience because of our child's challenging behaviours which is based on my recent research. That makes this book different from others you'll read about autism. There are plenty of excellent books about depression, anxiety, and stress but few about the trauma we experience because of our child's autism and associated behaviours. I say "we" because I've written this book as a mother of a child with autism and as a psychologist, to mothers of children with autism. This book isn't so much about parenting, but about how to cope with the challenges you face as a mother of a child with autism.

Who This Book Is For

Do you ever wonder if your best is good enough? Sometimes, it doesn't feel like it. No matter how hard you try, it feels like it just isn't quite enough. I'm here to tell you emphatically, that your best is good enough. Perfection is an illusion that can leave us heartsick and feeling like a failure. If you're the mother of a child with autism, regardless of your child's age, and you find mothering a challenge, then this book is for you. Are you longing for an open and frank conversation about how your child's autism affects you? You might be finding motherhood hard, but you don't really know why. Other mothers seem to be doing fine; why is it so hard for you? Do you need practical strategies that actually work and can be easily slipped into your busy life, between your child's therapy and meltdowns, to help you as a person and as a mother. Have you found yourself behaving in ways that you don't like, maybe having a meltdown yourself, or feeling ashamed, resentful, or sad at times and you don't know what to do with all that "stuff." I've written this book to you. I know you're doing your best. It's just really hard. You're enough.

Who This Book Is Not For

There are many books available about how to manage the behaviours of children and adults with autism. If that's what you're looking for, then this book is probably not for you. This book is written to mothers about themselves and how they can manage their own reactions, emotions, and behaviours in response to the incredible challenges they face. If you're going to be easily offended when I describe how annoying I find my son, then this book is definitely not for you. Please don't read it. If you're looking for a formal academic text to quote in your dissertation, then this book is not for you. This book is written in a conversational style.

Why Does This Book Matter?

This book matters because you deserve to understand what's happening to you, in your body, mind, and heart, because you're the mother of a child with autism. You also deserve to know what you can do about it in a way that's possible between therapy, meltdowns, work, and caring for everyone else in your family. It's time to care for yourself too. You matter!

You're doing an extremely difficult task that you never asked or volunteered for. Mothering a child with autism was thrust upon you. You weren't prepared, trained, or educated for this role you find yourself in. It's different than parenting a typical child. With a typical child, you can look around to your peers or ask your own mother what to do. Not so with a child with autism.

The usual things just don't work, and we don't always know why. It seems almost taboo to talk about yourself and the impact your child has had upon you. Well, he *has* had a huge impact, and it's time we talked about it.

CHAPTER 1

Who Am I And Why Am I Writing a Book to Mothers About Autism?

I'm Liz, a registered psychologist and mother of an adult son with autism and an intellectual disability. I'm also a work in progress and have not "arrived," despite my many years of being a mother and my many years of education. I have unique insights to offer from both sides of the fence as a mother and as a psychologist.

My first encounter with a psychologist was unpleasant, to say the least. I was a young mother with a toddler who had had a severe seizure. We had called an ambulance and he was in intensive care at the children's hospital for a few days having various tests and assessments. He was being assessed for brain damage because he had lost the little speech he had prior to the seizure, and had forgotten how to clap hands and open a sliding door.

* If you're busy, feel free to stop reading here. Below is a more detailed description of some of my journey with my son, and some of the "experts" we encountered. You probably have your own stories to tell about various experts you've encountered too.

I had found the psychologist to be very condescending. She spoke slightly louder than necessary and slowly. To add insult to injury, when she showed me my son's report, she had "white inked" out his scores. When I asked why, she said because I wouldn't understand them. As someone now trained in giving those same assessments, the scores aren't difficult to understand. They're percentages. It's not complicated! I felt small, stupid, and ashamed.

Several seizures later and another baby, I met with an even worse psychologist. She was a new graduate who took great pride in making me feel small and boasting she knew what she was doing because she had first-class honours! Well, she was a first-class "something" and didn't finish his assessment. She would threaten my son that if he didn't do the exercise she wanted, he could go home. He got up and stood at the door, ready to go home and refused to do more. He didn't want to be there and she offered him a way to get out of there.

She would rub his forearm as if she were trying to light a fire, to "reward" him when he complied. Again, she did the opposite of what someone who understood my child would do. My son was and still is tactile defensive and didn't like being touched. Rubbing his arm would have felt like a punishment rather than a reward.

She went to his kindergarten and took his food from him until he did what she wanted. I had consented to observation only. After a couple of sessions with Madame First-Class Honours, I asked my husband to take our son for the appointment. She stood over my husband while he was sitting of course, because he's over six feet tall, and pointed her finger in his face, telling him he had to do what she said 100% of the time or her brilliant behavioural interventions wouldn't work and it would be our fault. We were blamed and chastised relentlessly. I was disgusted and still am over 25 years later. The lack of respect, understanding, empathy, and compassion still astonishes and angers me.

Another year later, I decided to pay privately to have my son assessed. This experienced psychologist understood and listened. She also had trouble getting the assessment done but we got a result. However, she said he didn't have autism because he didn't walk on his toes. In the meantime, I had been taking my son to speech and occupational therapy, and he had been labelled hyperactive with attention deficit hyperactivity disorder, obsessive compulsive, and oppositional defiant disorders. We were fully immersed in the alphabet soup of ADHD, OCD and ODD with global developmental delay.

When my son was about 10 years old, we had moved states and encountered a pediatrician, whom we were seeing for ridiculous amounts of medications to manage my son's behaviours. I had wised up by this stage and had written a list of all his behaviours. I remember he swung back in his chair and decreed my son had PDD-NOS – "Pre-dinner drinks," he said with a laugh. It wasn't very funny to me. My son was diagnosed as having Pervasive Developmental Disorder - Not Otherwise Specified.

More letters for our alphabet soup life. I was left wondering what on earth does "not otherwise specified" even mean. He wasn't diagnosed as having "autism" until he was 17 years old. PDD-NOS no longer exists as a diagnosis since 2013 but was part of the autism spectrum criteria back in 1999. I have lived through much of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* changes in the criteria for autism spectrum disorder.

After being treated with such disrespect and inhumanity by psychologists, I vowed that, one day, I would become a psychologist and do better. I would treat my clients with respect and compassion, and not make negative assumptions about them. I hope that in my written words, you'll hear my voice filled with understanding, respect, and compassion.

Questions to reflect with.

Try not to dive into these questions and drown in the first chapter of the book! Just pick one example for each, even though you may have more.

1. What painful assessment experiences have you had because you're the mother of a child with autism?
2. Who were the worst experts you have seen so far on your journey with your child with autism?
3. What didn't you like, or what offended you?
4. How did you feel after you saw them?
5. Who were the best experts you have seen on your journey with your child with autism?
6. What did you like?
7. How did you feel after you saw them?

“The question is not how to survive, but how to
thrive with passion, compassion, humor and style.”
—Maya Angelou

Chapter 2

MODELS OF MOTHERHOOD ACROSS TIME

Summary

This chapter explains mothering traditions and social expectations for the last few hundred years. Some of the attitudes can still be felt today. The establishment and society aren't always correct in their expectations or legislation. I want you to think about the possibility that some of the expectations you have of yourself aren't your own or from your heart. You can be a trail blazer and march to the beat of your own drum, the rhythm of your own heart. You might just be right, and society might just be wrong. It has happened before, as this chapter explains.

If you didn't know it already, being a mother is tough, and being the mother of a child with autism is even tougher!

That's a fact![1] It's probably the hardest thing you'll ever do. As mothers, our Western culture has long placed demands upon us and expectations to conform to the social mores of the day.

Mothers of children with autism have experienced difficulty in trying to conform and fit in, as our children do socially unacceptable behaviours, and we reap the negative consequences of judgment, being misunderstood or ostracised for not fitting the expectations of mothers and children of the times we live in. But, are the expectations of society to be trusted or adhered to? Maybe not. The experts have been wrong many times before, as you'll see.

Historical Models of Motherhood

Surveying the recent history of motherhood may seem like a strange and boring place to begin this book, but I assure you, it's far from being either of those things. However, if you don't have the time or the interest to read this chapter, here's the point. Society has had all sorts of varying expectations over time, which have been shown to wrong! We can't measure ourselves as parents based on the values of others. They might be wrong. You are your child's mother, and as such you're in the best position to make choices about what's best. I promise if you keep reading the next few pages, you'll be amazed at how far we've come and maybe even feel proud of the changes that have been hard-fought and won by those who came before us.

As we take a glance in the rear-view mirror over the recent history of motherhood, we'll be able to see some of the changes that have occurred over time through the advocacy of some "warrior-hero" mothers.[2]

You'll be disgusted and inspired at the same time. I think it's worthwhile being reminded of your sisters' experiences, both struggles and triumphs, in the past, to see how far society has come, and where you want to go in the future. You can reflect on what kind of world you want your children to grow up in, and be the change-maker to bring it. Yes, you!

A Recent History of Cultural Models and Expectations of Mothers

When you think about period dramas like Jane Austin's *Pride and Prejudice,* you can easily imagine what life might have been like for the women of those times. One of the main themes of her books was for women to marry money and bear children.

In those times, women had few rights, and their primary roles were very clearly defined. Bear many children, in the hope that a few would survive and care for you in old age, if you lived that long, and carry on the family name. This was the case across all classes. Men worked and women birthed and raised children and ran the home. Infant mortality was high, and giving birth was hazardous.

CHAPTER 2

Segregation

During this time in the 1700s and 1800s, sadly, the “Ugly Laws” were passed, in which people with a disability were to be kept out of sight of the public so as not to offend people!

> Any person who is diseased, maimed, mutilated, or in any way deformed, so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares, or public places in the city, shall not therein or thereon expose himself or herself to public view, under the penalty of a fine of $1 for each offense (Chicago City Code 1881).

The disabled were considered disgusting and immoral, and here began the separation of people with a disability from everyone else. This occurred in the United Kingdom, the United States, and the Philippines. This was also the beginning of institutionalising people who were different. Imagine your child in that time. This attitude became an acceptable part of society, to reject the most vulnerable, the different, and keep them out of sight to avoid any feelings of guilt or awkwardness.

In 1913, Britain passed the Mental Capacity Act that further reinforced segregation of people with disabilities. Sadly, during this time, across various countries, the people who had been institutionalised were used for experimentation, which wasn’t limited to Nazi Germany. People with a disability were considered second class citizens if they were even considered human, often treated worse than animals, tormented and punished.

Parents were often forbidden from visiting, and gifts were not passed on to the children even up until the 1950s! Parents were expected to abandon their child to an institution. Mothers were often seen as the carriers of “bad seed” and were forced to “forget” their child. Children continued to be institutionalised until very recent times. I can only imagine the pain, blame, and shame experienced by those families. You see, the roots of rejection run deep and have had a long and shameful history.

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Forced Migration

In 1869, Annie McPherson founded a child migration scheme called Home Children. Over 100,000 poor or orphaned children were sent from the United Kingdom to Australia, Canada, New Zealand, and South Africa. While her motivation was good, to give children a better life, after seeing child slavery, the outcome was not.

Furthermore, between 1920–1970, 130,000 children were sent to the colonies for a better life, often children of single mothers or poor families. Children were told they were orphans. This number includes forced child migration following World War II.

During World War II in the United Kingdom, 2 million children were sent to the country to live with strangers, to avoid the bombings in London. Not all of them had the wonderful *The Lion, The Witch, & The Wardrobe* magical experience imagined by C.S. Lewis during World War II.

Apology - Oops, we were wrong.

In 2008, The Prime Minister of the United Kingdom, made a formal apology to the families of children who had suffered. The "Forgotten Australians" numbered 500,000, who were either sent from the United Kingdom to Australia as child migrants, first nation people taken from their families, children with disabilities or had behavioural challenges and were deemed "uncontrollable," or those who were in foster care or wards of the state.

The children were brought up in orphanages and foster care until the 1990s. In 2008, Kevin Rudd, the prime minister gave a formal apology. The experts, no matter who they are or where they come from, aren't always right! Take up your mantle of warrior-hero, and don't allow others to tell you to do something that doesn't feel right to you in your heart as a mother. When it comes to your child, you are the expert!

When it comes to your child, you are the expert!

As the twentieth century progressed, women began to find their voice and advocate to be heard for themselves and their children. Only in the 1970s were women granted equal pay in Australia, although whether that has been achieved is being hotly debated as inequality continues on that score.

Women were able to use birth control and have fewer children. This was a great contrast to the 1800s. Women were taking charge of their finances, families, and social systems, demanding change. However, the freedom to work didn't change expectations on the home front, where the hard-fought freedom to work came with a burden.

Mothers who worked were still expected to do most of the childcare and housework. It has taken decades for society to catch up to the change that if both parents work, both parents need to care for the children and contribute to the running of the home. Happily, this has been changing in this century.

Integration

Integration rather than segregation is being legislated today, with demands for equality for everyone, not just the smart, rich, or beautiful. The different and disabled may no longer be discriminated against. In Australia, we have seen the introduction of the National Disability Insurance Scheme and a Royal Commission into the treatment of people living with a disability. While the world is not perfect, and we still need warrior-heroes, we are seeing significant progress in our lifetime and positive change in the social fabric of our society.

This century continues to see rapid social change. Although mothers work, they spend more time with their children than mothers of the 1950s. Fathers are more involved in childcare and household tasks.[3]

Social Media

Social media has been an influence for a long time. Today, we have the Internet, which can be both a blessing and a curse. People often post about their best moments, making their life appear pretty and easy. Other mothers can appear to have it all together and know just what to do to avoid embarrassment in public. They seem to be able to work, raise great kids who are doing well in school, who are compliant and obedient. It can lead to everyday mothers feeling like failures, especially mothers of children with autism who have behavioural challenges.

The bar for being a good mother has been set unrealistically high. Mothers may be afraid to reach out for support and explain the extent of their challenges for fear of being trolled or condemned. This is why we need Donald Winnicott's[4] reassuring voice from the past to speak into the lives of modern mothers about being a "good enough mother."

Questions for reflection

1. What social expectations do you feel? What do you think others expect of you?
2. Are they fair and reasonable in light of your child with autism?
3. What expectations do you have of yourself?
4. Are they fair and reasonable in light of your child with autism?
5. Do any of the above expectations not sit well with you, not match your particular situation or not beat in time with your heart?
6. What painful experiences have you had because of the expectations of others in relation to your child with autism? Name only one now. You're likely to have others.
7. How did you react at the time?
8. How did you feel at the time?
9. Did you do the best you could with the resources and knowledge you had available to you at the time?
10. Is there anything you'd like to change?
11. Write this statement and say it out loud like you mean it, even if you don't just yet. **My best is good enough!**

> "Do the best you can until you know better. Then when you know better, do better."
> —Maya Angelou

Chapter 3

PSYCHOLOGICAL MODELS OF MOTHERHOOD

Summary

We're going to explore some of the theories about children and mothers that have been developed by leading and renowned psychologists. Many of these theories are still in use today, and some, like Freud, have echoes that still ring out in our culture.

There have been various psychological models for motherhood, trying to define what a good mother would do and be for her children. Some have brought comfort and others condemnation and judgment that still influences attitudes today.

Sigmund Freud

Sigmund Freud has been the source of many funny memes on social media with the tagline "It's your mother." I find Freud's sexually explicit explanations of childhood development quite shocking. It surprises me that his theories were taken seriously and so widely accepted, given the time in history and their vulgarity. However, Freud's theories did gain traction and popularity especially in the 1940s. His theories have been the foundation for mother blaming since that time.[1]

The Refrigerator Mother

This ties in with the first use of the term "autism." In 1943, Leo Kranner noticed children who had speech difficulties, social isolation, and unusual behaviours.[2] He also noted, possibly influenced by the prevailing Freudian theory of the time, that the mothers of these children with autism appeared cold with a "genuine lack of maternal warmth."

In a 1960 interview, he described the parents of children with autism being able to "defrost just long enough to produce a child." Bruno Bettleheim further reinforced autism as being a parenting disorder, suggesting this group of children would benefit from a parentectomy![3]

The first challenge to the "refrigerator mother" didn't occur until 1964, when Bernard Rimland, a psychologist and parent of a child with autism, published his book, *Infantile*

Autism. (Yay! I love our tribe.) Although Leo Kranner tried to correct the record and reported that he had been misquoted and misrepresented, the theory took hold in the medical community when no physiological explanation could be found.

Though wholly discredited today, the "refrigerator mother" diagnosis condemned thousands of autistic children to questionable therapies, and their mothers to a long nightmare of self-doubt and guilt. About this same time, however, other theories were developing that were more compassionate toward the role of mothers. My favourite is Donald Winnicott who, in the 1950s, coined the term "the good enough mother."

Donald Winnicott - The Good Enough Mother Advocate (My Hero)

Although Winnicott had no children of his own, he seemed to have developed a beautiful interpretation of motherhood, filled with understanding and compassion. Winnicott spoke of how children attach or bond with their primary caregiver, usually their mother. His term "holding environment" describes the infant being held in his mother's arms, but also a safe and comforting environment from where a child could explore.[4]

A central theme was the suggestion that a child needs his mother to fail at times and not be 100% available, so the child could pass through developmental stages. The child learns that the world is imperfect. The child develops a tolerance to his needs not always being attended to immediately and in the way he wants.

The titrated or drip-fed levels of frustration help the child develop and realise the world doesn't solely revolve around him. This news may surprise many parents and children today! They do not, in fact, have control over their mothers. Building resilience and tolerance in children is a gift. I am not endorsing neglect in any way! I am only suggesting that children learn and grow when mothers disappoint them at times, usually not on purpose.

Imagine if you have a toddler who needs his potty, the baby needs feeding, and the 4-year-old is pulling the cat's tail and has just been scratched. These are all "emergencies" requiring attention, but someone will have to wait and consider others' needs as well as his own. This is a good thing.

It's impossible for any mother, unless they happen to be an octopus, to immediately attend to each of these "disasters" simultaneously. What the "good enough" mother can do, though, is put the 2-year-old on the potty, perhaps the baby and the 4-year-old are crying by this time, then comfort the 4-year-old, put the cat outside, and get the 4-year-old to snuggle up to her while she feeds the baby. Everybody is fine and all have been attended to, but somebody had to learn to wait.

John Bowlby and Attachment Theory

Around this same time, in the 1950s, John Bowlby developed his “attachment theory,” which explained the importance of early interactions between mothers and babies. At the time, the neuroscience that now validates Bowlby’s theory, wasn’t known for sure, but was more intuitive.[5]

Bowlby was largely scorned in his day, as what he was proposing didn’t fit in with the prevailing Freudian theories of the time. Today’s neuroscience can now confirm that Bowlby was right, and that the interactions between mothers or primary care givers and babies is essential to their development.

John B. Watson and Conditioning

John B. Watson is the father of conditioning and behaviourism, which means giving a reward for good behaviour and a punishment for bad or unwanted behaviour. This theory was outdated and over 50 years old when I met my second psychologist, Madame First Class Honours. She was trying to enforce “behaviourism” upon me and my son with autism, and blaming me when it didn’t work.[6]

This theory hung around for far too long in psychology circles unfortunately. There is a place for rewarding appropriate behaviour of course. What Watson proposed was scheduling children for sleeping, feeding, playing, and when they could be hugged and receive affection. Scheduled feeding is a concept that has been around since then. Mothers were advised not to respond affectionately when their child cried because it would create self-centred, spoiled children.[7]

Time out is a form of this behaviourist parenting model. You can read my encounter with Madame First Class Honours, who was a staunch behaviorist, in the introduction, which explains my bias against it. But then, along came Dr Spock, who turned that style of parenting on its head.

Dr Benjamin Spock

The 1950s and 1960s was a time of radical change in Western society and someone leading the charge for change in parenting was the pediatrician Dr Spock, the author of *The Common Sense Book of Baby and Childcare.* It's one of the best-selling books of the last century, selling over 50 million copies.

He became quite a controversial figure that was both loved and hated vehemently for his beliefs about parenting. He went completely against the typical and popular theories of the time. He had the gall to suggest that parents could be flexible and child-centred. People argued these ideas would make children spoiled and demanding.

Spock was a breath of fresh air for mothers who flocked in droves to buy his book and follow his parenting suggestions.

Mothers were told to relax, treat their children as individuals, hug them, and have fun. Every child is different; trust your instincts, he suggested. He wasn't advocating for permissiveness but rather for relaxing some of the rigidity around parenting at that time.

* Read this next part even if you're busy. The advice is still good today!

Some of Spock's advice is still relevant today. He told mothers that they were the experts about their child, not doctors. Mothers ought to listen to their "gut feelings" and use their intuition and do what they thought was best for their child. Don't worry about what neighbours, friends, or family members say, but focus on the needs of each particular child. Bond with the child and give affection freely. He was suggesting mothers be motherly, rather than the barrack sergeant demanding unquestioning obedience.

Dr Diana Baumrind and The Four Parenting Styles

Following years of observations, Baumrind suggested that there are four basic parenting styles.[8]

Authoritarian

Authoritarian parents use strict discipline styles, usually including some form of punishment. This style fits into Watson's behaviourist style in many ways. Communications are mostly one way, from parents to children, often with little explanation of any rules set in place.

Permissive

Permissive parents are also called indulgent parents, and mostly allow their children to do what they want and have what they want. There are usually few rules and children are expected to figure things out for themselves. Communication is usually in both directions, but parents allow the child to make their own decisions, rather than giving direction. These parents are usually warm and nurturing.

Uninvolved

Uninvolved parents, also called neglectful, give their children lots of freedom. Sometimes, this is because they don’t know what to do or they’re just not interested. The child experiences a lack of information, direction, and care. Communication is fairly minimal; the parents have no expectations of the child, and give very little nurturing.

Authoritative

Authoritative parenting is considered the most effective and beneficial for children and parents. These parents set clear goals and expectations, while, at the same time, are nurturing. Rules and expectations are clearly explained to the child, communication is frequent and in both directions where the children often have a say about the goals and discipline strategies used.

Emotionally Intelligent Parenting

This seems to be the predominant theory now. Emotionally intelligent parents are trying to be smart about their own feelings and the feelings their child might be experiencing. We used to have "time outs." Now we're advised to have "time ins." Parents are encouraged to sit calmly and be understanding, compassionate, and empathetic while their child has a meltdown for example.[9]

Questions for Reflection.

1. With so many theories to choose from, which one feels right and resonates with you?
2. What do you like about that theory?
3. Does it fit with your children and your child with autism in particular?
4. Have you thought about which theory might work best for which of your children?
5. Which theory did you like the least?
6. What didn't you like about it?
7. What new perspectives about parenting style did you get out of this chapter?
8. What's one thing you're going to do differently?

CHAPTER 3

Encouragement - How I Became My Team Leader

I want you to know that you're the best mother your child could have. No one loves him more than you, or knows him as well as you do. You're the expert, and you can be the team leader with other helpers and experts coming under your authority, and being subordinate to you on your team. You might wonder how I got to that stage?

I remember coming home from school drop off, and going in the shower so I could cry in peace! I remember thinking often that if something went wrong while I was in the shower, it wasn't my fault.

I had a powerful image flash into my mind of being on a wild black horse, galloping furiously, lathered in sweat, with me on his back, struggling to hang on to his mane that was whipping me in my eyes. I felt terrified, afraid, and powerless. I cried out to the Lord angrily, "Why did you give him to me? I don't know what to do with him. Why didn't you give him to an expert like a psychologist? Why me? I can't do this."

I recall expecting a compassionate response from God, comforting me in my wallowing and self-doubt. (My experiences with God aren't usually like that!) I felt God reply, "I've given you everything you need to do this. Toughen up and get on with it!"

Well, what a slap in the face, and a slap back to reality. I realised I had begun to believe I was stupid and incompetent, until God slapped me in the face. I was stunned to say the least. It was quite calming, actually. After I dried and dressed, I dug out my old school reports to remind me and reassure me I wasn't stupid!

From that day, everything changed for me. I used to attend appointments feeling small and ashamed. I would walk into the offices of the experts with my tail between my legs so to speak. But not after that day! I rediscovered my self-confidence, walked tall, looked the experts in the eye, and began making demands, asking questions, and wanting explanations. This was a very significant moment in my life that changed me forever. I became a warrior-hero mother.

Exercise:

Think back on a time when you've felt small, incompetent, and not enough as a mother. OK, stop that now. Let's not live there! Now, make a list of some of the times you've been a great mother, the sacrifices you've happily made for the benefit of your children. Think of a time you were a warrior-hero mother, advocating for your child. If you haven't done that yet, that might be a new goal for you. It's OK to "stick up" for your child. It's OK to "stick up" for yourself too. You don't have to be obnoxious.

Theodore Roosevelt said, "Speak softly, and carry a big stick; then you will go far." Our big stick is the confidence we have that we are the expert in our child's life, and we are the team leader. We don't accept bullying from anyone, be they experts, professionals, other parents, our family, or friends.

Speak softly and carry a big stick;
then you will go far.
— Theodore Roosevelt

Chapter 4

UNDERSTANDING THE DIAGNOSIS OF AUTISM

Summary

This chapter will cover the changes in diagnostic criteria for autism and where it is today. This can be useful information because the diagnostic criteria are used to determine the level and types of supports we can access for our children and the level of funding they may be eligible for. Understanding the criteria will help make you a better informed and therefore more effective advocate for your child. You can find a 2-minute video here that's a great summary:

https://www.youtube.com/watch?v=Rhqr0giWz7Y&feature=emb_title

Changes in the Diagnostic Criteria for Autism.

Sometimes, understanding the diagnostic criteria can help you phrase the needs your child has in terms that experts may be more inclined to listen to. Sometimes, using their language helps them understand your child better. It can help you understand what your expert is looking for and you can help them if you know a little about the criteria.

Sometimes, you adapt so well to the behaviours of your child that you stop noticing and forget to mention it when it may meet some of the important diagnostic criteria that your expert needs to know. It can also help you know what questions to ask and what to tell your expert when you don't always know where to start.

When talking with your expert, be sure to describe what could happen on your worst day, not your best day. Cry, without shame, if you need to and express your true emotions! You're not there to impress your expert with your coping skills but to communicate as effectively as possible, with emotion, what your child is really like. Don't sugar coat with optimism. This is serious business.

When talking with your expert, be sure to describe what could happen on your worst day, not your best day.

The diagnostic criteria have evolved to reflect the changes in understanding autism. The *Diagnostic and Statistical*

Manual of Mental Disorders (DSM)[1] is the handbook used by healthcare professionals in much of the world as the authoritative guide to the diagnosis of mental disorders. The *DSM* contains descriptions, symptoms, and other criteria for diagnosing mental disorders.

The first time autism was entered into the third edition of the *DSM* was 1980. It was described as a pervasive developmental disorder, separate from schizophrenia. (This is noteworthy because previously autism was originally described as childhood schizophrenia by Leo Kanner in the 1940s as we discussed in the previous chapter.)

Early Years of Diagnosis

Kanner described "extreme autistic aloneness, delayed echolalia and anxiously obsessive desire for the maintenance of sameness." At the same time, he noted children were "often intelligent and some had an extraordinary memory." Autism was viewed as an emotional disturbance, not affecting cognition.

The second edition of the *DSM* that was published in 1952 defined autism as a psychiatric condition and a form of childhood schizophrenia that was marked by detachment from reality, which was caused by cold, unemotional "refrigerator mothers." This view of mother blaming continued until the 1970s, when evidence began to emerge about the biological and neurological nature of autism.

By the 1980s, when the *DSM III* came out, autism was recognised as a developmental disorder. It was revised in 1987 to include the subcategory of pervasive developmental disorder - not otherwise specified (PDD-NOS) for children who didn't entirely meet the criteria for autism but had many of the features of the disorder. In this decade, three main areas were identified which included a lack of interest in people, severe impairments in communication, and bizarre responses to the environment, developing in the first 30 months of life.

For the first time, in 1994, the *DSM IV* and the 2000 *DSM IV-Revision*, recognised autism as a "spectrum." Five conditions were included in the spectrum. In addition to autism and PDD-NOS, Asperger's disorder, childhood disintegrative disorder, and Rhett syndrome were added.

During this time, it was hoped that following the Human Genome Project, specific genes for autism would be linked to each subcategory, but this didn't occur.[2] As a result, autism became characterised as an all-inclusive spectrum, ranging from mild to severe.

Diagnostic Criteria at Present

The changes in the conceptualisation of autism led to this being reflected in the most recent *DSM 5*, published in 2013. Autism is now characterised by two group features: the persistent impairment in reciprocal social communication and interaction, and restricted, repetitive patterns of behaviour, both being present in childhood.

Asperger's, PDD-NOS, and Rhett syndrome were eliminated from the manual in the autism category, but placed in a new category of social communication disorder which would include children with only language and social impairments.

Autism now has one category with three levels of severity ranging from level 1: requiring support, to level 3: requiring very substantial support. Diagnosis of children with autism in Australia is often provided by a multidisciplinary team which may include pediatricians, speech pathologists, occupational therapists, and psychologists; however, unlike the United Kingdom, there is no standardized procedure at this time.

The fallout from the changes in diagnostic criteria meant that some people became ineligible for services. People with milder autism are more likely to not receive a diagnosis and, hence, receive no support services.

Lina Zeldovich, in her excellent article published in *Science* explained that some people with Asperger's syndrome, for example, felt that removing that category took away an important part of their identity, that had helped them understand and explain their experiences.[3] They felt a loss of belonging to the autism community. It has been suggested that the new criteria may make it more challenging for girls with autism to receive a diagnosis.

The *DSM* is not the only diagnostic manual. The ICD-10 (*International Classification of Disease,* 10th edition) is similar, but intended for more international use and has less culturally specific criteria and broader guidelines. It also makes a point of highlighting that adults, and women in particular, with autism, may sometimes mask their autistic traits.

Question for Reflection

1. Have any of the changes in diagnostic criteria affected you? In what way?
2. Have the changes been better or worse for you?
3. Now you know more about the criteria, how can you use it to phrase some of the needs your child has in a style that experts will listen to?
4. Describe your child's worst possible day, what they did and to whom.

Chapter 5

BEHAVIOUR CHALLENGES WE FACE

Summary

Many of the challenging behaviours of our children with autism are dangerous and cause a great deal of stress. It's not just your imagination that most other children aren't engaging in these behaviours repeatedly. Some of the statistics below are quite heartbreaking.

I share them so that if you're parenting a child with any of these behaviours, you know you're not alone or to blame or a terrible mother. It's so easy to blame ourselves and accept the condemnation of others. The behaviours are part of the disorder, not the result of bad parenting. If you find some of the information in this chapter distressing, feel free to stop reading.

Challenging Behaviours Are Common

You're not alone if you experience challenging behaviours with your child because 94% of children with autism have some kind of challenging behaviour[1] and 88% of parents find managing the behaviours to be a problem.[2] Our children with autism often have challenging and dangerous behaviours, which are more common and extreme when there is also an intellectual disability present, which is the case for about 70% of our children.[3] These may include destruction of property, poop smearing, verbal and physical aggression, and escaping and running away with the risk of drowning or other serious accidents.[4]

The more severe the autism and the greater the number of other psychiatric disorders happening for your child, the greater the risk to the mother of depression and lower quality of life. I felt quite overwhelmed as I did my research to realise that my son had done all these things!

Meltdowns

Often children with autism have persistent patterns of crying, not sleeping, agitation, and tantrums, where the parent spends considerable time dealing with "meltdowns."[5] Approximately half of children with autism experience high anxiety, depression, and irritability.[6]

Escaping

Escaping and running away is a serious risk factor for 50% of children and teenagers with autism.[7] It usually starts around four years old and peaks around five and a half years old, with the risk increasing with the severity of autism. It has been reported that 24% of escapees were at risk of drowning and 65% at risk of a traffic accident.[8]

Escaping and running away is the highest cause of death for children with autism aged between five and ten years. It's been found that 29% of children with autism escaped several times a day, 35% at least once a week, and 43% of parents couldn't get a good night sleep due to remaining awake to keep their child safe.

I can remember when we had just moved into our new house and our son was about four years old. We woke up one morning and couldn't find our son anywhere. It was such a terrifying feeling. We hadn't yet secured the property so he couldn't escape. He hadn't done anything like that before.

As it was a new area, construction was going on all around on other houses. We called out to tradesmen on the roofs of other houses asking if they had seen him. Thankfully, our neighbour over the road was a policeman, and he helped us search for our son. He was found around the corner, hidden behind a large shrub, and was brought home. We realised we needed to ramp up our door and window locks.

CHAPTER 5

Self-Harm

Approximately half of our children with autism deliberately hurt themselves. They may hit themselves in the head, bite their arms or fingers, throw themselves on the furniture, poke their eyes, or pick their skin, creating sores.[9]

Head-banging is common and one of the main causes of hospitalization or even death for our children.[10] The usual age for self-harm is eleven to twenty-five years with an average age for this starting being around twelve years old.

Having a child who self-harms is very distressing. My experience has been different than the averages found in research. Our son began banging his head while he was still a toddler. I can remember wanting to have a family portrait taken, and waiting for the scabs on his head to heal over from where he banged his head on his cot.

It took me a while to realise that he seemed to always have a scab on his forehead. He would also bang his head on the floor or the walls. Sometimes, he had black eyes. I felt worried going to the shops with him for fear of what others would think of me.

Now he's an adult in his thirties and he still bangs his head when he's upset. His plans may have had to change if a support worker is unable to come for example. He'll bang his forehead with his wrist or on his knee. He's quite flexible!

Sometimes we don't know he's doing it, and by the time we hear the banging, he already has a sore head and neck from the jarring and wrist or knee from the hitting. It's taken a long time for me to learn to stay calm, offer comfort and empathy, and get some ice and a paracetamol because he's going to have a headache!

Suicide

Suicidal ideation (thinking and talking about suicide), suicide attempts, and completions are more common in older adolescents with autism than neurotypical adolescents.[11] Higher functioning children are more at risk of suicide because they have more mental capacity to plan and complete a suicide than children with less intellectual capacity. Depression is common for adolescents with autism.[12] Risk factors include social isolation, abuse, being bullied, and being male, which probably covers most our children.

Being Bullied

Reports have been as high as 94% of children with autism experience bullying, higher than any other disability.[13] You may have marched up to the school many times, feeling outraged, wanting to sort out the bullying problem your child is experiencing. You may have been met with contempt, eye rolling, disdain, and a general attitude of, "Not you again."

Your child and/or you may have been labelled as problematic or a nuisance. You may find yourself constantly complaining. Is it any wonder when you know that so many of our children are on the receiving end of bullying? They're the most vulnerable children, rather than the most annoying (although that could also be true).[14]

> Our children don't need to "toughen up," but other children and the community need to "soften up" and be compassionate and understanding.

Children with autism are twice as likely to experience physical and sexual abuse than typical children, leading to suicide attempts and running away.[15] Children with autism are at the greatest risk of filicide-suicide, where 55% of children with disabilities murdered have autism. The tragic implication being that life with autism is not worth living for the child or the parent, and death is the only reprieve.

Despite research that confirms children with autism often also have challenging behaviours, few measures or assessments quantify or rate and describe the behaviours. Often, multiple behaviours are grouped together.

A possible reason for this is that although up to 70% of children with autism present with challenging behaviours, it's not considered a core feature of autism. I find this surprising and unhelpful. This may go part way to explain why behaviours aren't always the focus of an assessment or supports provided. It may also explain why the struggles parent's experience with their child's behaviours can be easily dismissed and categorised as bad parenting.

Questions for reflection.

1. What behaviours of your child do you find the most troubling?
2. What have you tried to cope with your child?
3. How do the behaviours affect the rest of the family?
4. How can you support your other family members when the behaviour is happening?
5. What can you do differently in response to the behaviours of your child?
6. What do you do after the behaviour is over?
7. How do you feel before, during, and after the behaviour? Include emotions and physical reactions like racing heartbeat and your own behaviours.

Chapter 6

RISKS TO MOTHERS OF CHILDREN WITH AUTISM

Summary

As mothers, we are most often the primary carer for our child. The stresses of raising a child with autism have some important negative consequences.[1] Becoming aware of the risks we face can help us better manage ourselves. We are at risk, and we need to be mindful to take care of ourselves as well as our children and family.

We know that mothers of children with autism experience more stress, depression, and anxiety than mothers of typical children. Although these three are often bunched together and often occur together, they're different. We are also at greater risk of poorer physical and mental health than mothers of children with other disabilities or typical children. The challenging behaviours of our child can pose a threat not only to himself, but to us and others, including his brothers and sisters.

Depression

What we know is that mothers of children with autism experience a higher incidence of depression than mothers of typical children.[2] Depression is more than feeling sad or a bit low sometimes. Everybody has those moments and that's part of being human. Feeling depressed sometimes and having depression are different.

Depression is characterised by a feeling of hopelessness about the future, feelings of wanting to give up because it's not worth trying, feelings of worthlessness, and thoughts about death and dying. You might feel like this most of the time.

Up to half to two-thirds of us experience depression, which is a lot higher than the typical 15% in the rest of the community. It has been shown that the more severe our child's autism and behavioural challenges, the more likely we are to be at risk of experiencing depression.

Another suggestion made is that depression may be higher for us if we feel responsible for the cause or the outcome of our child having autism. This is when we might feel we can't do enough for our child and not feel good enough as a mother. Trying to parent alone may also increase the risk of depression.

Loss and Grief

Aside from the challenging behaviours we encounter, often, other things are going on for us. Receiving the diagnosis, although it might be a relief at the time, is also a loss, which may be accompanied by grief.[3]

Our child with autism is not going to be like our other children or our neighbour's children. They may not play sports; we won't be on the sidelines cheering them on. They're less likely to be invited on playdates and we're less likely to be included in events or get togethers because of our child.[4] These things represent very real losses that we're unprepared for.

Finances

We may find we need to leave our work, and the income that it produced, to stay home and care for our child. In my research, I found that over 40% of mothers were unable to work because of their role as a carer for their child.[5] This represents a significant loss of money coming into our household.

Having a child with autism, may also represent money going out of the household to pay for therapies and interventions or even upgrading security, replacing things that get broken, or trying to compensate our other kids for the difficulties they experience.

Sleep Deprivation

Sleep deprivation can also increase our vulnerability to depression. Many of us have experienced disrupted sleep over many years, and it’s a genuine challenge to stay upbeat and positive when we’re dead tired.

We may also become irritable. On top of being sleep deprived and irritable, we may have to put on our warrior-hero, and advocate and fight for the rights and needs of our child, in a David and Goliath battle. The despair can feel overwhelming and depressing at times.[6]

Parental Aggravation

Parental aggravation is measured using four simple questions. The quiz is designed to measure levels of frustration and stress parents experience while raising their children. Parents of children with autism have shown higher scores on this quiz.[7] Did you feel your child was harder to care for than most children? Did your child do things that really bothered you a lot? Have you felt you were giving up more of your life to meet their needs? Have you felt angry with your child? If you have a child with behavioural challenges, it’s easy to see how the scores for this questionnaire would be higher than parents of typical children. My research found that over 90% of our mothers experienced high levels of aggravation in parenting.

Anger

Some interesting research has also shown that anger can be a significant factor that contributes to feelings of depression. This is interesting because two variables contribute to our feelings of depression. One is that the severity of our child's behaviour can be related to depression. The other, though, is that our depression can feel worse, depending on how we react and interpret the behaviours of our child.[8] This is exciting because it's something we can choose.

We may react to a behaviour and feel angry. The angrier we feel, the more depressed we might feel, which could add further to our feelings of anger. I wonder if anger is something we don't often acknowledge or talk about?

You may have read blogs and Facebook memes glorifying the raising of a child with a disability. You may have heard or been told how blessed you are that God gave you this special child. God must have known you could handle it. Well, that just doesn't resonate with me! I have days when I can't handle it. It feels beyond my capacity to cope!

Emily Perl Kingsley, the mother of a child with Down's Syndrome, wrote the insightful poem "Welcome to Holland." We dreamt of having a typical baby, which would be our planned trip to Italy. But we didn't get what we expected when our child with a disability showed up! So, instead, we still have a lovely trip to Holland. Let me be honest here! I don't want to go to Holland because it's awful, not an alternative happy reality for me.

Having a child with autism with behavioural challenges is not similar to having a typical child, which is difficult in itself. The level of difficulty escalates to be off-the-chart difficult. My child, if he were in Holland, would be throwing wooden clogs at me and his siblings. He would be ripping up the tulips in the gardens and kicking in windmills. He would be up in the middle of the night, rummaging through the fridge, eating all the Edam and Gouda before any of us got a taste.

My experience is that parenting a child with autism has been awful, devastating, and terrifying, and I wish it were different. I wish he were different. I have had times when I've been beyond angry and felt intense rage. I have shouted so hard that I actually saw stars! It's a wonder I didn't have a stroke or heart attack. I'm not proud of my reactions. But I share them and own them to help you know that if you've experienced this, you're not alone. You're not a bad mother. You're human! You're understood and not harshly judged by at least one other person on the planet.

Actually, come to think of it, having a child with autism it is a bit like Holland. When we were in Amsterdam, bikes were everywhere and had complete right of way; we had to adapt and maneuver to accommodate them, and, while walking, I was frequently almost bowled over. It was terrifying trying to walk anywhere, and I never want to visit Amsterdam again because of it! Maybe Holland is more similar to autism than I thought. (Link to original story is at the end of the chapter).

We also know that anxiety is more common among our tribe. Anxiety and depression are often lumped in together but they are, in fact, quite different. It's a bit like two siblings being known as the "Blues Brothers." They're individuals who are related, but not the same.

Anxiety

We all feel anxious at times. If I were going to skydive, which I never would, I might feel anxious before the jump. That would be a typical reaction. Anxiety is more than occasionally feeling anxious. Anxiety is a state of being constantly worried about the present or the future and that something will go wrong. The feeling that it might be better to avoid a situation rather than have it get out of hand. It shouldn't be surprising when we consider the types of behaviours our children engage in, that we would experience anxiety!

If our child escapes frequently, risking harm and being in danger, and we seem unable to secure him safely at home, we would feel anxious about his potential to escape. If our child has frequent bouts of screaming and shrieking, which disturbs not only ourselves but perhaps our neighbours, who wonder what we're doing to our child, we would feel anxious in anticipation.

If our child has meltdowns when we venture out in public, and we know that once they start, the trip is over, we would feel anxious. If we have to get everyone back in the car when they were looking forward to the outing, we may also have to deal with the disappointment and embarrassment the siblings feel about what just happened. The pressure is truly on. Whether the disaster actually happens is almost irrelevant. The worry and dread that it will, based on previous experience, is almost as bad.

Stress

Stress is different from anxiety. Stress is defined in the *DSM 5* as "the pattern of specific and nonspecific responses a person makes to stimulus events that disturb his or her equilibrium and tax or exceed his or her ability to cope." What this means is that something happens (stimulus) and affects our ability to cope with the situation. The greater the thing that happened, the greater the stress. Again, it's not really surprising that we may experience greater levels of stress than mothers of children with other disabilities or typical children. When we consider the types of behaviours our children do, they do tax our capacity to cope.

Physical Health

Our physical health and well-being have been shown to suffer. We are 40% more likely to die from cancer, 150% more likely to die from cardiovascular issues, and 200% more likely to die from accidents.[9] Well-being is measured in a variety of ways and it can measure optimism, social support, stress, or emotional self-regulation.

Emotional Self-Regulation and Isolation

Emotional self-regulation is how well we manage our own big feelings. The thinking is that if you're more optimistic and have greater social support and self-regulation, you have higher well-being.[10]

It might be hard to feel optimistic at times when we know autism is a lifelong diagnosis, and progress can be very s-l-o-w. We can feel more discouraged than optimistic. Having connection with others and support is another important factor that can improve our well-being.

Feeling isolated is a significant indicator of how well we'll cope. Feeling alone can be soul destroying. A few things might happen that can leave us feeling alone and unsupported. A big one is the behaviour of our child. Our children do socially unacceptable things that are annoying to others. They annoy us as well, I'm sure, but where do we go to resign? As my mother would often say, "The complaints department is closed."

We might be unable to have a cohesive conversation like we used to because we're hypervigilant about his behaviour. Will he run off, hit, spit at, or bite someone else's child; strip; or scream his head off? The list of "unacceptable" behaviours is endless. It's easier to not invite us if we have to take our child with us.

Rejection

We are faced with the stigma, judgment, and condemnation for not having trained our child properly, and some people don't want to be around that. It's uncomfortable for them, so they exclude us. Other times, we may choose to exclude ourselves because an unknown disaster may occur, and we fear the embarrassment and shame. Eventually, our friends stop inviting us because we always say no.

It's shocking but true that sometimes even our own families reject our child. Often, the harshest criticisms come from within our own families. Sometimes, it can be hard for them to cope with the reality that it's not just other people's children who have autism, but now it's in their own backyard. This can make it difficult to avoid feeling uncomfortable or to keep old prejudices or preconceived ideas buttoned up.

Relatives don't know what to do with your child either. Grandparents may not want to babysit because of your child's behaviour. Family members also have imaginings of what the new baby will be like, and they might not want to go to Holland either! They may experience grief and loss as well.

Your child may not have bonded with them in the way they hoped. They may not have been cute as a baby, but irritable and crying all the time. They may not want a cuddle or a hug or to kiss grandma. They may refuse to eat certain foods and then have a meltdown, making family dinners difficult if not impossible. Relatives may feel angry with you and your child because you always manage to spoil family get-togethers. They start to wish you wouldn't come. They may also stop inviting you.

Despite my mother-in-law working at a special needs school and volunteering as a babysitter for children with a disability, she never had any of our children visit or stay over – even our typical children. I recall one occasion when it was someone's birthday. She called us to say, "We're having a birthday dinner. We're letting you know so you don't show up on the day." I called one day to ask if we could visit, and my father-in-law said, "No, I have to wash the breakfast dishes." There were only the two of them and they were retired. The declined visit wasn't about the dishes. It can be very painful when the people we hope will, and even expect to, support us will reject and exclude us.

Overcoming Loneliness and Isolation

Feeling alone can be diminished by reaching out to our tribe. You may do this on social media perhaps. Join a group or two or three or more. Share your struggles and your wisdom gained through your own journey.

Being part of an online community, you have the opportunity to receive but also to give. It lets you know you're not alone, and there are many others in the same boat. Actually, the rate of autism is now around one child in 68[11] or maybe more if girls with autism were better understood. By joining a group, you don't have to explain everything and try to get someone to understand how hard parenting your child can be. They get it. They know.

Reaching out for formal supports can also help reduce feelings of isolation. Many community supports are available. You might be having speech or occupational therapy. Talk to your therapists. They're not your friend, but hopefully they're friendly and give you support and advice.

As much as you can, develop a positive relationship with the professionals in your life helping your child. Think of it as a partnership, rather than them being the expert and you being the underling who must comply. A partnership is far more productive. Consider becoming the team leader and view them as part of your team. You're the most important therapist in your child's life. Don't be afraid to step up and lead.

Do We Feel Competent as a Mother?

Another area to consider is how we feel about how we are doing as a mother. Do we feel like we're doing an OK job? This is one area that can take a big hit. The thoughts we have about our ability to effectively parent can influence our levels of stress and depression.[12]

Our thoughts can be shaped by the type of feedback we get in our everyday lives. We might interpret our child's difficult behaviour as a challenge to our parenting ability, or we may interpret it as a threat or rejection, particularly when we're struggling.

Our feelings of being incompetent or inadequate as a mother, can be reinforced by the negative feedback we might receive. It might not even be words. It might be a sneer or a look of disgust or even of pity from a passerby. It might be your mother telling you to do better or try this or that, which you know will never work for your child. It might be getting called up to the school yet again because of your child's behaviour.

When we experience feelings of guilt or shame, we feel less adequate. We might feel guilty about how little time we have available to spend with our other children because of the demands of our child with autism. When we feel stressed and or depressed, we may feel less capable or effective as a mother.

We can feel disempowered and trapped in a role we did not ask for or prepare for.

Our Relationship with Our Partner

Another consequence we may experience because of our child with autism is a decrease in our feelings of satisfaction and closeness with our partner. With the demands of our child with autism, the needs of our other children, and the guilt we might feel for not being able to meet them, our partner's needs and wants as well as our own, can take a back seat.

You may have moments when you have a stand-off with your partner related to who is going to deal with that behaviour this time. When you feel stressed, you might think your partner should step up, forgetting that they may be feeling stressed as well. It is almost impossible to connect in an intimate way when we are stressed and distressed.

We may find ourselves in survival mode with no resources for connection. Connection could be a kind look, a kiss, a conversation, or sex. All these connecting behaviours are hard to do under stress, and before we know it, we feel distant from our partner, and negative feelings can build up that further impact our relationship.

A more recently understood consequence of being the mother of a child with autism is that of trauma. My research showed that 31% of us meet the criteria for posttraumatic stress disorder or PTSD.[13] I'll cover this in detail in the next chapter.

Questions for reflection.

1. What risks or consequences have you identified from reading this chapter?
2. Click here to take the Depression, Anxiety, Stress assessment called the DASS-21, developed by Lovibond &Lovibond. https://www.scu.edu.au/media/scueduau/current-students/services/counselling/downloads/Depression-Anxiety-Stress-Scales-DASS3481.pdf

3. How did you score? If you have high scores it might be a good idea to see your doctor or reach out for some therapy. You don't have to do this alone.
4. Isolation can be a serious issue for our tribe. What's one thing you can do to reduce some of your feelings of isolation? Who can you reach out to? Maybe a Facebook page with fellow tribe members or call a friend or get some professional support.
5. Write down one *specific* action you're going to take. What's the name of the Facebook group, or what's your friend's name?

Welcome to Holland can be found here:
https://www.cedarsstory.com/welcome-holland-interview-author-emily-perl-kingsley/

PART 2

Chapter 7

MOTHERS' EXPERIENCES OF TRAUMA

Summary

This chapter will explain the experience of trauma for mothers of children with autism from my research and others. This is an emerging area of research.

You may have noticed that, although I explained a bit about depression, anxiety, and stress, I didn't go into a lot of detail. There has been a lot written about these subjects already. My hope is to give you something new to think about.

What Is Trauma?

Trauma can be explained as events that pose a significant or perceived threat to the safety of yourself or your loved ones, and are shocking or overwhelming. This seems like a very apt description of what parenting a child with autism feels like!

What we know so far is that mothers of children with autism experience similar levels of stress, that can be measured using saliva cortisol levels, as Holocaust survivors, first responders like paramedics or police, soldiers returning from combat, and people with PTSD.[1]

This tells us that for some of us, living with our child is like being in a warzone! Can you relate to that? This is not an everyday garden variety of parenting stress. If you're finding your role as mother difficult, you're right!

Some Indicators of Trauma

Mothers of children with autism have *lower* levels of the stress hormone cortisol than mothers of children with other disabilities or mothers of typical children. Is that a typo? I said "lower" levels of the stress hormone cortisol. That's correct. Surprising, right?[2]

It might make more sense for mothers to have higher levels because they're more stressed. It's lower because people who experience a lot of trauma have blunted cortisol responses. This tells us that our bodies are responding to our situation in a similar way as other groups of people who have experienced trauma or have PTSD.

What we also know is that people who experience lots of traumatic events are more vulnerable to experiencing PTSD. Sometimes, a series of "small" traumas, sometimes called "small t" traumas can build up and result in PTSD. Although some people can get PTSD from one "big T" trauma, like an accident or natural disaster, we know that experiencing increased stress over a long period of time increases the risk of someone developing PTSD.[3]

What Does This Mean for Us?

Some of the behaviours our children do qualify as traumatic. The *DSM 5* criteria for PTSD includes exposure to death, threatened death, actual or threatened serious injury. This includes when these events happen to us or we hear about them happening to a relative or close friend.

When our child bangs his head, leading to injury and a trip to the hospital, that's trauma. Head banging is a leading cause of death for children with autism.[4] When your child escapes from home and is at risk of being hit by a car or drowning in the pond at the local park, that's trauma.

I found my child jumping on our trampoline with a bread knife in his hand, with the risk of hurting himself or someone else. This is a "threatened serious injury." When your child attacks one of his siblings or you, that can be traumatic. When he destroys your house and breaks things in a rage of distress, you may feel a genuine sense of threat, especially if your child is bigger and stronger than you.

The harm autistic children may do to themselves can be distressing, especially if they've thrown themselves on some furniture or bitten or cut themselves. If you don't feel safe with your child, who is now two metres tall and much bigger than you, this can be experienced as traumatic.

If your child has attempted or completed a suicide, that can be traumatic for any parent. Often, our children don't do these behaviours just once. They're often repeated anywhere up to multiple times a day. As mothers are most frequently the primary carers, we often have the greatest exposure to these repeated traumas.

In addition to what your child actually does, there's also the trauma of hearing how your child has been bullied or assaulted. This is called "vicarious trauma" when you hear about it. These events do meet the description in the *DSM 5* where an event has posed a significant or perceived threat to the safety of the individual or their loved ones.

Symptoms of PTSD

Bad Memories

PTSD comes with several symptoms. Some of the common symptoms reported by the mothers in various research[5] were that they experienced upsetting and unwanted memories of incidents related to their child. Some reported flashbacks or nightmares about certain events. These are called "intrusion symptoms." That means things pop into your mind and affect you when you don't want them to.

Avoidance

Another category outlined in the *DSM 5* is avoidance. We might tend to avoid situations that trigger our memories. We may also experience negative thoughts and feelings, like blaming ourselves, when an incident wasn't our fault, like our child being a world-class escape artist like Houdini.

Depression

We might find that we feel down, lose interest in activities, and have negative thoughts about ourselves and the world around us. We might feel irritable or behave more aggressively than we used to. We might be on high alert often and have trouble concentrating and sleeping in addition to our child keeping us awake during the night.

Startle Response

Some symptoms you may be familiar with like having a heightened startle reaction - we might be a bit "jumpy" in some situations. When these kinds of symptoms start to impact our relationships and our work, we know we have a problem.

There's a quiz link at the end of this chapter if you would like to see how you're doing in relation to PTSD symptoms. While 31% of mothers met the full criteria for PTSD in my research, many reporting having many of the symptoms.

Even if we don't fully meet the criteria for PTSD, we can use the quiz to identify what areas we are finding difficult, so we can become aware of what's happening within ourselves and address some of those symptoms.

If you notice something that's important for you, don't dismiss it or minimise it because you don't meet the whole criteria. The goal is not to just get a label. It's to become aware of how you're doing and how you're being affected by your child and his behaviours.

Questions for reflection.

1. Did you do the exercise at the end of the last chapter? What did you do to reduce your feelings of isolation?
2. How has that been working for you? Has it been helpful or not?
3. Do you need to try something else? If so, what?
4. Here's the link to the PTSD quiz. Keep your child with autism in mind as you answer. https://www.ptsd.va.gov/professional/assessment/documents/PCL5_Standard_form.PDF
5. How did you score?
6. How did you feel about some of the questions?
7. What new insights have you gained from doing the quiz?
8. Do you meet the criteria for PTSD? If yes, I encourage you to seek support from a therapist. PTSD is a very real thing that will impact your life and the lives of those you love so dearly. Reach out for support.
9. Did you reach out for support? Why or why not?

10. What stopped you?
11. Can you do anything to remove those obstacles? Are they excuses because you feel scared or ashamed?

There is no shame in what you’re experiencing.
You’re a human on the front line of a war zone.

Chapter 8

WHAT TO DO ABOUT TRAUMA.

Summary

In this chapter, you'll learn about the polyvagal nervous system and how we respond to trauma in our bodies. This is a very important chapter. I recommend you read this one, even if you're busy. It's not one to be skipped.

So far, we've covered a lot of bad news! Now let's get on with what we can do to better manage our experiences, emotions, and lives. First, it's important to understand that we're not looking to blame anybody, least of all you! Our aim is to understand and, from that, figure out what we can do to make our lives and that of our children and families better.

Although I'm a psychologist and talk for a living, sometimes, talking doesn't help. If you're anything like me, you don't want to explain what your life is really like. Just talking about it is exhausting, then trying to get someone else to understand can be frustrating or hurtful when they offer flippant advice. So, what else is there? Let's begin by looking at what happens in our body when we experience stress and trauma. Don't be scared about the terminology. I'll explain everything as we go.

The Polyvagal Nervous System

You've probably heard the line, "What happens in Vegas stays in Vegas!" It's similar with our nervous system. What happens in our polyvagal nervous system can often stay in our nervous system, repeating old patterns, even when they're no longer useful. This theory was first developed by Dr Stephen Porges. It is the science of feeling safe and what happens when we don't feel safe.

What happens to us, and how our body responds to those experiences, can set a pattern. This is more than psychological and just in our head. When we feel scared, our body responds, because a chain of physical events has been set in motion. Two of the experts in this field are Bessel van der Kolk who wrote the excellent book, *The Body Keeps Score*, and Peter Levine who wrote *Waking the Tiger*.

I've found it interesting that throughout my eight years of full-time study, this information wasn't covered in any of the courses. Yet, for me, it's been the most life-changing and useful information professionally and personally. So, now I'm sharing it with you.

Without making it complicated, the nervous system has three parts I want to tell you about. I'm going to talk about three different levels to make it easy to remember and understand. Level 1(L1) is how we feel when we're relaxed, Level 2 (L2) is how we feel when we're activated or stirred up, and Level 3 (L3) is when we feel like we're frozen in place. Let's begin with Level 1.

Level 1 Calm, Connected, and Social.

Level 1 (L1) is where we want to live as much as we can. We are relaxed and able to engage with others socially. This means we can listen well to others; speak with expression using tone, pitch, and loudness; and use our faces to express our feelings, so the other person can see how the conversation is going.

We can send positive messages to them through the way we use our body, including the movements we make. In L1, we feel safe and relaxed, and we can be flexible and spontaneous. Being flexible helps us to respond to our environment when we are socialising in a positive way.

For those who like a bit of technical information, L1 is also called the ventral vagal complex, which is part of the parasympathetic nervous system. When we are in L1, our social engagement system is activated and is using the myelinated vagus, which creates calm behavioural states. It does this by stopping or inhibiting the sympathetic nervous system that influences heart rate and keeps a lid in our other stress systems such as the HPA axis. That's a term used to represent the interaction between the hypothalamus, pituitary gland, and adrenal glands and plays an important role in our stress response.

When we're in L1 our digestion is working; we have better immunity and good circulation to our skin, hands, and feet; oxytocin, the bonding hormone that allows us to relax without fear, increases; our voice is rhythmic and expressive; and we move our heads and eyes more. As a result of feeling safe, we feel calm; we can be curious, settled, and present.[1]

Level 2 Fight/Flight, Defensive

Level 2 (L2) is where we go when we feel upset. We might feel afraid, frustrated, irritated, angry, or in a rage. We may also feel fear, panic, anxiety, worry, and concern. When we are in L2, our defensive system turns on and our socialisation system turns off. L2 is also known as the "fight/flight" zone. Our body has sensed danger and is getting ready to run away or defend itself. We're no longer in the mood for socialising in the stay and play zone.

To get a bit technical, L2 is part of the sympathetic nervous system. To get ready to respond to the perceived danger, our blood pressure, heart rate, breathing, muscle tone, and adrenaline increases. More oxygen starts flowing to our vital organs, blood clotting capacity increases, our pupils get bigger, and so do our bronchi, so more oxygen can get to our lungs.

When we're in L2, we burn more physical energy, insulin activity increases, we make less saliva, and may experience a dry mouth. We're not very good at relating to others, and our immune response goes down. Some things slow down when we're in this state such as our digestion and gastrointestinal functioning.

Interestingly, when we're in L2, we might respond with aggression or withdrawal to the same warm and engaging stimulus we had when we were in L1 and felt safe and connected. Our interpretation of the same situation changes when we're in L2. It can be very difficult to dampen down our L2 reactions and get back into L1.

We stop using our facial muscles to express ourselves, we lose the expressivity in our voice, and we're no longer able to listen very well. We use our hands, eyes, and head in a different way. Imagine someone feeling angry and holding their hands in a tight fist by their sides. We become rigid physically and, certainly, less mentally flexible.

This helps us to understand what's going on when we feel upset, whether we're scared, anxious, or angry. Our body starts doing things by itself when we're in this negative state. When our children or partners are in this state, they won't be able to hear us or process answers to any of our questions.

This can help explain, for example, that when couples argue, they say the most ridiculous or hurtful things that they would never say when they were calm, and possibly don't even mean. We get defensive. After everyone calms down, we can be left wondering what on earth just happened.

You might relate to how our child might be upset, so to be helpful, we yell at him to calm down! Or is that just me? We might feel regret or shame.

Level 3 Freeze, Shut Down, Play Dead, Immobilised

Level 3 (L3) is where we hope we'll never be! L3 is where we feel terrified and perceive a threat to our life. This where we freeze, become immobile, shut down, or collapse. In L3, we feel like we're powerless and can't do anything. Some interesting things happen in our bodies. Our heart rate, blood pressure, temperature, muscle tone, facial expressions, and eye contact become less.

We can imagine ourselves "turning white." Breathing becomes shallow, our immune response decreases, and we find it difficult to impossible to do social behaviours and interact with others around us. We start conserving our energy and our insulin activity increases. We become immobilised, and our happy neurotransmitters, such as endorphins, which help numb pain, also increase.

Evolutionists relate this to an animal playing dead before they're eaten, so they don't feel the pain. I don't subscribe to evolutionary theory myself but intelligent design by God, but the reality is the same regardless of the theory we think is behind it. When we are in L3, the freeze zone, we can feel helpless, depressed, hopeless, trapped, shut down, or a sense of feeling outside of our body, feeling dissociated, disconnected, or disembodied from ourselves. We may feel numb or ashamed.

Getting a bit technical again, the L3 is also known as the dorsal vagal complex, which creates a passive reaction to immense danger or terror. Part of the decreased muscle tone leads to people wetting or pooping themselves. The body is thought to do this to reduce the demands of digestion. The body is trying to reduce the physical demands upon it to the barest minimum.

I've reflected on this and recall being told how calm I was when I arrived in the ambulance at the hospital with our son, who was having a very long seizure. I used to think that was a good thing, and maybe, at the time, it was. Actually, I was in a state of terror, shut down, and disconnected from my emotions.

I used to think that getting upset and crying wouldn't help, and that was true. What I didn't realise then, was that I wasn't calm, I was in freeze. This is also a common reaction for people who've been raped or abused. Victims wonder why they didn't shout, scream, or fight back. Defence lawyers have had a field day blaming victims for not fighting back. Victims were beyond scared or angry, as they were in the grip of absolute terror, and were immobilised.

Sometimes, although these reactions were right at the time, and could have been how we stayed safe, as life goes on, those same reactions no longer serve us. Instead, they make trouble for us, as we repeat old reactions, and our body remembers, sometimes, when we don’t.

We use “neuroception” to help us figure out when we’re in danger and when we’re safe. Sometimes, those signals don’t get updated and we “get our wires crossed.” We might react negatively, aggressively, or withdraw when we misinterpret signals from those around us. Neuroception is like our Spiderman superpower that sets our “spidey senses tingling.” So, what exactly is neuroception?

Neuroception - Our “Spidey Senses”

Our nervous systems are continually checking out our environment and making decisions about danger and risk. We use information from our environment and from our “viscera.” What’s viscera? It’s all our inner, essential parts in our main body cavity or hole, such as intestines, stomach, and heart, for example. Interestingly, our neural conscious awareness is not required for neuroception. It happens outside of our awareness usually.

Neuroception can tell the difference between what’s actually in the environment and how our body responds to it and can tell us if we’re safe or in danger without thinking about it. If we had to think about it, sometimes, it would mean we would be dead. It's just a sense we might have to grab our child from the curb. We react without thinking. It's intuitive, a gut feeling.

When we feel safe in our environment, our sympathetic nervous system (L1) is dampened. Neuroception helps us do social behaviours by helping us tell the difference between safety and danger. It helps us with regulating or controlling our emotions and keeps our visceral state steady, in homeostasis - unchanged (L1) rather than activated.

In this state, parts of our brain can help us respond to the intention of someone's voice, their hand gestures, and movements. For example, the neuroception or spidey senses reactions we have when we are with someone familiar and safe who has a sing-song voice with highs and lows, warm expressive facial features help us to know we are safe and promotes social interactions. This is when we are in L1 and feeling sociable.

Our viscera or inner parts also send messages to our brains telling us what's safe and dangerous. How our body reacts influences our perception of objects and those around us. When we're in L2 or L3, we're not very good at reading positive social cues and we may react as if we're in danger when we may not be. When our body is reacting, we know our heart rate, breathing, and digestion change. In L2 (fight/flight) the viscera ramp up, and in L3 (freeze) the visceral organs slow down to the minimum required to survive.

CHAPTER 8

What Goes Wrong?

Sometimes, however, our spidey senses or neuroception and visceral communications are wrong! They tell us we're in danger when, in fact, we're not. Sometimes, there is a mismatch with what we're feeling and experiencing in our bodies and the facts of our environment. An example of this is when someone who has been in a warzone hears a firecracker explosion that reminds them or triggers them to feel how they felt during a battle.

Although the war is long over and they're back home thousands of miles from danger, the person's body will switch from L1 to L2 or L3. They will not have thought about it, but their body will have reacted. Their heart rate and breathing may increase, which will tell their brain they're in danger. They may be under the table before they know it. When they calm down, they may wonder how they ended up under there.

They didn't choose to do that. Their spidey senses told them there was danger when they heard that explosion and *reacted*. They didn't act with intention or planning. They may say they couldn't help it, and they would be right, if they didn't understand what was happening in their nervous systems and body. Their body and mind need to be reprogrammed and retrained to recognise when they're not in danger.

There can be all sorts of triggers from our senses. It could be a smell, a colour, or some other sensation that sets off our alarm system. It has been described as being like a smoke alarm. You can burn the toast and the alarm will go off just as loudly as if the house were on fire. The body needs to learn to tell the difference between burnt toast and the house burning down. Often, when our feedback and messaging systems are broken, it's due to some form of trauma.

Creating Change

Top-Down Processing

To create change, something has to change right? Two ways to create change are called top-down and bottom-up processing. I like to remember top-down as using your brain to change your thoughts and body. Bottom-up is using your body to change your brain and thoughts. When we are in L1, and feeling calm and sociable, we can use top-down processing. Our brain and mind are engaged and receptive. We are able to be flexible and curious. We can retrain our brain to think differently.

When we're upset and activated, scared, or angry, we can no longer use our brain for top-down processing because our thinking part with its higher level of intellectual functioning has shut down. When we're upset, we can't think or reason our way out of it. In this state, nobody else can help us either by using reason or talking because, in this activated state, we are no longer very good at listening or interpreting social cues. We become defensive and either withdraw or become aggressive. This is when we can switch to using bottom up processing. That's using our body to send messages to our brains.

Bottom-Up Processing

Bottom-up processing is a good way to interrupt our feelings and behaviours. We can use our body to tell our brain we're safe and to calm down. In our brain, there is a little organ the size of an almond, called the amygdala. This is a very important little organ because it's our smoke alarm sensing danger. When it senses danger, it sends our body into L2 (fight/flight) or L3 (freeze).

Without thinking, our inner parts get ramped up to prepare us to either run away from danger or stand and fight. Our heart will race, our breathing will become fast and shallow, and we may break out in a sweat. The easiest and only really effective way to turn off the smoke alarm and tell your brain you're safe is to breathe.

Just Breath - Seriously!

Telling someone to just breathe sounds really lame, right? We might answer back that we're too upset to breathe more slowly. That's not true. You can! Taking a long, slow, deep breath in and a long slow exhale is the only way to manipulate your body to make your heart slow down. Slowing your heart down by taking slow breaths, tells your brain you're safe, and it can turn off the smoke alarm. It was only the toast burning after all.

When we or our child are upset or both of you at the same time, if you start taking a deep breath, your child may mirror your behaviour and calm down. We have these amazing cells in our brains called mirror neurons. This is how we influence others. We can use our super powers for good, model a new calming behaviour for our child, and calm ourselves in the process. Just like our brain can tell our body we're in danger, and our heart rate increases etc., our body can send the message to our brain that we're safe.

Before we can use bottom-up processing to get our body to communicate to our brain, we need to develop our interoception. What that means is that we get to know our body and become aware of our reactions and in what situations they occur, especially the negative ones! Our body and brain are linked to our emotions. How complex we are!

If we aren't very good at recognising what's going on in our body, we're less likely to be very good at managing our emotions and our state (e.g., L1, L2, or L3). Sometimes, when we've experienced a lot of trauma, being present in our body has not always been a safe place, so we might be in the habit of ignoring the messages we receive from our body, brain, and emotions. Getting back in touch with our body can be quite daunting.

If this feels overwhelming for you, think about talking with a therapist who can create a safe space. A therapist can help steady the ship and "contain" the overflow of emotions that can feel too big to hold on your own.

Questions for Reflection

1. Can you recognise the three states of the polyvagal nervous system?
2. Can you think of a time when you were in each zone?
3. What have you tried before to calm yourself?
4. Did it help or not?
5. Why or why not?
6. What's one thing you're going to try that you haven't tried before?

Chapter 9

UNDERSTANDING THE IMPACT OF TRAUMA

Summary

Knowing and understanding our bodies is the first step towards managing our own reactions, behaviours, and emotions. This chapter isn't a rule book, but a series of suggestions you can try and adapt to you! You're unique, and I'm not offering one size that fits all. I'm asking you to do some work on you, get to know yourself in more depth, and then figure out what works for you.

Emotional Self-Regulation.

Emotional self-regulation is crucial in how we manage ourselves and our children. When we are being traumatised by our children's behaviour, it's even more critical. As we know, we may be facing not only trauma but also depression or anxiety, which can impact our capacity to parent the way we would like to.

It can be very easy to look around at the school gate and among our friends and neighbours and notice how great they are with their children. Their children seem so much easier to manage than our own. It looks that way because it *is* that way.

What we know for sure is that mothers like us have a much more difficult job parenting our complex children than other parents. So, be kind to yourself and acknowledge that you have a difficult task in your role as a mother to a child with autism.

What Does a Traumatised Parent Look Like?

Mothers are more likely than fathers to have PTSD in general.[1] At this stage, I don't know how fathers of children with autism are coping or how traumatised they may be. I asked only mothers to answer the questions about their child with autism. Unfortunately, fathers tend not to participate in research surveys.

What I found in my research using the PTSD Checklist for *DSM-5* was that mothers of children with autism experienced many of the symptoms from the questionnaire. (See previous chapter for link to questionnaire). In fact, almost a third experienced PTSD symptoms at levels high enough for a provisional diagnosis of PTSD. It's called a provisional diagnosis because the questionnaire is used as a reliable measure for screening who needs a more in-depth interview.

Common Symptoms of PTSD That Mothers Experience

Here's a list of the symptoms from the questionnaire. Mothers said they experienced unwanted memories and/or dreams of a stressful experience with their child with autism. They felt they were reliving a stressful event at times and felt they were back there. They felt upset when something reminded them of a stressful event with their child with autism and tried to avoid reminders. They found they experienced some strong physical reactions when those bad memories popped up, like the symptoms we talked about for L2, (fight/flight) of sweating, increased heart rate, and trouble breathing. Sometimes, they couldn't remember the whole of the stressful experience, only parts. They said they felt jumpy, were easily startled, super alert, and had difficulty concentrating, falling asleep, or staying asleep.

Strong Negative Beliefs About Themselves

Other symptoms mothers experience include having strong negative beliefs about themselves, such as something must be wrong with them; the world is dangerous; blaming themselves after something has happened; strong feelings of horror, fear, anger, guilt, or shame; loss of interest in activities they used to enjoy; feeling distant and cut off from people; trouble experiencing positive feelings of happiness or loving feelings for people close to them; feeling irritable; having angry outbursts or acting in an aggressive way; or taking risks that could cause them harm.

What Does PTSD Feel Like?

Having PTSD or any of the symptoms can be awful! You can see from the list above, that these things are going to affect your parenting, and you're probably going to blame yourself and feel hopeless. Feelings aren't always true! They absolutely feel true, but sometimes, they can be skewed by our own wrong perceptions of the situation and of ourselves.

Feelings aren't always true! They absolutely feel true, but sometimes they can be skewed by our own wrong perceptions of the situation and of ourselves.

When we think about our children and the things they do, especially the dangerous things they get up to, it's hard to not to be reminded of the last time they did the thing. Painful memories and sensations can come flooding back, and they're fairly hard to avoid. Your child is hitting or banging his head repeatedly. He's showing no signs of stopping and you're worried.

First, you're faced with the tough decision of what to do! You know it's not good for him to keep banging his head. If you're like me, you're going to feel upset and start moving into L2 (fight/flight). I have felt worried, angry, and scared at the same time.

Then while my brain is overloaded with the L2 reactions, my heart is pounding, and I'm sweating, I've got to try to use my brain, which is shutting down right now, to decide how to handle this situation! It's cruel! I need to make a good decision, but my reactions and body conspire against me.

Shall we go to accident and emergency? We've tried that before. We wait for ages and are scowled at the whole time. I sit frozen (L3), worrying if I might be accused of abuse or being treated with contempt as the bad mother I already think I am.

Public shame and humiliation send my stress through the roof. The "experts" won't be able to stop him either, without sedation. Oh no, a needle! The situation goes from bad to worse in my mind, based on what happened previously. All the while, my child continues to bang his head. What can I do? I need to find a way back to L1, to be able to think straight and solve my problem.

Chapter 10

CHOOSING YOUR REACTIONS

Summary

This chapter has information about recognising reactions and what your options are based on polyvagal theory.

What Are My Options for Managing My Reactions?

Reaction One

I've got three possible options based on polyvagal theory. Honestly, previously, I've just gone to L2 or L3. I felt L2 (fight/flight) and became angry, started shouting at him to stop it (really helpful, right?), felt myself shaking, panting, clenching my fists like a child having a tantrum and my heart pounding. I seriously lost it! You don't need me to tell you that my reaction, which was happening because I was having a trauma response, not because I was a bad mother, was in no way helpful for my son.

Maybe somewhere in my brain, I knew it, but I wasn't able to stop losing it and having a meltdown myself. I'm using headbanging as one example, but he would do all sorts of dangerous, destructive, or just plain annoying behaviours. I could melt down on a regular basis, sadly. There always seemed to be something!

Option Two

The second option is to go beyond the L2 (fight/flight) and into L3 (freeze). At this level, we know we essentially shut down or check out. We become immobilised, and may look like we don't care as in "Whatever, knock yourself out, literally." When we are in L3, we are completely overwhelmed and overloaded with stress, panic, and a sense of doom. I can reflect and know I've also been at this level.

At L3, I just don't do anything. I walk away or ignore the situation. There's no yelling; there's just nothing. I can recall this feeling like being the living dead. I had many days when I'd wake up in the morning and be disappointed. I would think, *Damn! I gotta get up and do today!* My wake-up call would be my son banging on his door shouting or screaming. It's not a good start to a day. I wasn't a bad parent when I was having a trauma reaction in L3, but I certainly felt like one. There was plenty of self-loathing going on.

The Good News Third Option

Now, for some good news: there's the third option. This is what I try to do nowadays and I've found it has worked for us. I now know that I can use my body to down-regulate and calm myself. My son still hits himself when he's upset. I am better at anticipating his reactions these days and have a much better understanding of what he might be feeling.

In the old days, when I'd get upset and have my own meltdown while he was having his, I wasn't able to empathise and see the world from his point of view. I need to be in the calm L1 to be able to do that.

When I see his meltdown coming, I pause and take a big deep breath. (I still grimace a bit inwardly, sometimes, thinking, *Not this again.* If I swear, I know I'm in angry L2 and need to get out of that thinking quickly and switch to empathy for my son). I get in the L1 calm zone.

When I see his meltdown coming,
I pause and take a big deep breath.

I go to him immediately and empathise. "It's hard for you when things change. I can see you look upset about that. It's hard, isn't it? I understand. Do you feel like you need to hit your head? That helps sometimes, doesn't it?"

I empathise rather than criticize.

Creating a Holding Environment.

I ask him if he would like me to sit with him while he's thinking things through and deciding on his course of action - to hit or not to hit himself. I don't get too close because he doesn't like that. I ask permission to be with him while he's upset. I might sit on his bed with a gap between us.

Sometimes, he says no. In that case, I just lean in the doorway to his room, breathing deeply and steadily. This is not huffing in a temper. His mirror neurons are going to pick up my state. I'm physiologically calm in my body, I'm breathing steadily, I'm feeling empathy and compassion in my heart that's radiating towards him. I'm not judging him for feeling what he's feeling or doing what he's doing. I'm just there with him. This is sometimes called a "holding environment."

A holding environment is something that my hero, Winnicott spoke about, in his series about the "good enough mother." He explained that mothers hold their child in their arms, but they also create a "holding environment," where they hold their child emotionally. The concept has also been called "containing," when someone else takes the overflow of emotions that are overwhelming the child, and contains them for him.

This idea has been reborn with the concept of the emotionally intelligent parent. Often, our child is not able to regulate himself. He needs us to help him. This is called co-regulation and we do it by regulating or calming ourselves.

It's not wrong for him to feel angry, frustrated, disappointed, or confused. Our children may not be able to express how they feel, so they do behaviours.

Our children may not be able to express
how they feel, so they do behaviours.

Behaviour as Communication

Every behaviour is communication. These days, I try to figure out what my son is trying to tell me when he's doing a behaviour rather than try to stop him or control him. He needs a way to express himself when he can't find the words. By staying around, when he's upset, I'm also narrating what's happening for him. I'm giving him words for what he's feeling and that can be helpful.

This sounds lovely, doesn't it? How sweet and calm. Does it always work? No! The reason it doesn't always work is that I still have trouble staying calm sometimes. I do this better sometimes than others. When I do it impatiently and haven't got myself into the L1 calm zone enough, things don't go so well.

I'm still learning to down-regulate myself after more than 30 years of being triggered and having meltdowns myself. However, I'm getting better at it and can do it faster now than before, which is increasing my success rate. You can learn to do this too, which is my hope and prayer for you, warrior-hero mum.

We need to be calm to be able to hold or contain our child's emotional overflow.

It can be almost impossible to remain calm when you have a child with autism. Everyone has needs and you're expected to meet them, and you probably want to be able to meet them. You might have days when you no longer recognise yourself because you seem to behave like a crazy person. Where did the old you go?

These days you may find yourself irritable with a really short fuse. Nothing seems to please you or make you happy any more. You may feel guilty about that when you have so much to be thankful for. Or you chastise yourself that your children were just doing childish, and completely age-appropriate annoying things, like spilling stuff or being messy or forgetful. Even knowing that, you feel like you can't stop yourself being snappy with them. You can sometimes experience feelings of guilt or shame for not being a better mother.

Why It's Hard to Love Yourself.

Another set of symptoms of PTSD includes having strong negative beliefs about yourself and blaming yourself. As a mother of a child with challenging behaviours, I didn't need any extra help with these! I already felt like a bad mother. To make me feel worse, it was hard to have any positive feelings about myself or my son. He didn't make it easy to love him as it was.

Not having loving feelings for my child was confronting. We're supposed to, right? Good mothers love their children and *feel* like they love them? It's tough. I found it hard to find loving feelings for my son sometimes because he never gave me any feedback to let me know I was doing OK.

The feedback loop in parenting goes both ways. I have felt like my son hated me at times, and was deliberately trying to ruin my life. I didn't feel like this every day, but there were quite a few when I did! Part of the challenge with this concept of feeling love is that when we're traumatised, it's one of the things that can go.

We can end up feeling numb, not feeling love for the people around us, whom we know in our head we care about. We just don't feel it anymore because of trauma, not because we're bad people, psychopaths, or unloving mothers. Sometimes, through no fault of our own or anyone else's, including our child, we can't feel like we used to. This happens when we're in the blue freeze zone, and we've shut down in some areas because of the trauma. We've been stretched beyond our capacity, and something has to go. Sometimes, it's our capacity to feel.

Behaviour Isn't Personal

Another challenge I faced when I and my son were younger and I was an inexperienced parent and young human, was that I would take his behaviour personally. I would feel like he was ruining my life on purpose. These feelings made it hard to experience loving thoughts towards him.

The anger and frustration I felt about my ability as a parent, became directed towards my son. I would ask myself, “Why is he doing that. Why doesn’t he stop doing that? I can’t stand it when he does that. Ugh, he’s done that same stupid thing again! Now I have to fix it or clean it up. *Why are you doing this to me?*”

My son’s behaviours were relentless. There always seemed to be some disaster happening. My responses due to my state didn’t help either! Often, on reflection, I can see that my reactions escalated the situation, rather than calmed it. It’s hard to feel the love when nothing lovely ever happens!

It was a great revelation when I realised his behaviour wasn’t directed at me. His behaviour was about him and his needs and his inability to express himself, remember, and learn from past situations, and not being able to predict what the consequences would be due to his intellectual disability. I’m not sure how I managed to make myself so central to his behaviours and take them personally.

His behaviour was about him and his needs and his inability to express himself, remember, and learn from past situations, and not being able to predict what the consequences would be due to his intellectual disability.

Questions for reflection

1. Do you experience any of the symptoms that describe PTSD?
2. Which ones?
3. What's a "holding environment"?
4. How might you create a holding environment for your child?
5. What's one thing you can do when you and your child are upset to calm so you can co-regulate?
6. What's going to make calming difficult so you can co-regulate?
7. Is there anything you can do differently to incorporate calming and co-regulation with your child?
8. What have you done well this week, even though it was really difficult?
9. What's one thing you're good at and like about yourself? (Nothing is not the correct answer!!)

Chapter 11

WHY PTSD IS SCARY

Summary

PTSD can be scary because we may have feelings of terror or horror that can be hard to tolerate at times.

Another effect of PTSD and feeling traumatised is that we may have strong feelings of fear, horror, anger, guilt, or shame. As mothers of children with autism we may be vulnerable to feeling like we're a failure as a mother because our child isn't doing what everyone else's child is doing. He may be socially inappropriate for example.

It's easy to blame ourselves for not being a good enough mother and teaching him better. This is not true. My experience is that you often cannot reason with autism. We experience many more trial and error situations with our parenting that can lead to feelings of failure. This may intensify any feelings we have of guilt, shame, or anger.

We experience many more trial and error situations with our parenting that can lead to feelings of failure.

What about feelings of fear and horror? There are plenty of things to be fearful about. We may be afraid we'll be embarrassed. We may fear being rejected by friends and family or even people who don't know us who want to chip in with their condemnation when we're at the shops, for example, and our child has a meltdown because it's not Tuesday! It's a fear of social death in a way.

We lose our identity as an individual who is unique to become the bad parent of "that" child. We can lose ourselves and our connection to who we thought we were and what used to make sense to us. Often, autism behaviours just don't make sense to us in a neurotypical world. We learn to understand them over many years, but in the early days, we are puzzled, frustrated, and may wonder who we are. We can become lost and can feel like we're drowning in an ocean of autism.

We may be fearful of the danger our children put themselves and others in, including their siblings and us as their mother. A frustrated, enraged, violent person who is six feet tall is scary, especially when you know you cannot reason with them in the state they're in. They may punch a hole through the door, hit someone close by, or smash things like your new television.

Not only can the behaviour be frightening, but if you're living in a rental home, then there may be additional worries. Even when we know our child cannot emotionally self-regulate and understand why it's hard for them, it doesn't make the violence any less frightening. How do you protect yourself or any younger children when these types of outbursts occur? How do you stay calm and co-regulate in such a terrifying situation? It's reasonable to feel fearful.

You may have a child who lives by a busy road and frequently runs away. No matter what you do, he finds a way to escape and put himself in danger. When you can't find him after you went to the toilet for five minutes, you may begin to feel panic rising. Rightly so.

Hypervigilance - Why It's Hard to Relax.

With the kinds of behaviours our children do, it's very difficult not to become hypervigilant. It's almost unavoidable. Possibly the only time we may not be hypervigilant may be when we're in the L3 shutdown zone because we're feeling overwhelmed to the point of terror. We've become immobilised, rather than hypervigilant. That's not good either! What do we do? It's difficult. We'll feel jumpy and easily startled.

We might hear a noise in the night and know that our child is an escape artist. We cannot ignore that noise. Many parents find they're unable to get a good night's sleep for this reason. Over the longer term, that can make us irritable as well. In addition, you may have a child who simply doesn't sleep. You've tried everything and still, they don't sleep, and neither do you. You'll have difficulty falling asleep and staying asleep. In this hypervigilant and sleep-deprived state, it's going to be difficult for us to concentrate and pay attention.

Depression.

As mothers of children with autism, we are more vulnerable to depression. An aspect of PTSD is to lose interest in things we used to enjoy. That's also one of the symptoms of depression. Other symptoms of depression include not being able to experience any positive feelings at all, finding it hard to start things or get things done, having nothing to look forward to, feeling downhearted, not being able to feel enthusiastic about anything, a feeling of having no self-worth and that life is meaningless.

As mothers of children with autism who most likely have behavioural challenges, it's understandable that we may experience some or all of these feelings. This can be especially true if we have little success in managing our child's behaviours. We can become overshadowed with a sense of hopelessness and experience depression. Feeling depressed can affect our mothering because it reduces our capacity to tolerate some situations and act to make things better.

Has Your Child Been Traumatised?

We need to consider that our children may have been traumatised in addition to the challenges they face with autism and any other diagnosis they may have. There is often an “alphabet soup” diagnosis that might include oppositional defiant disorder (ODD), attention deficit disorder with hyperactivity (ADHD), obsessive compulsive disorder (OCD). Your child may have others.

If all that wasn’t a heavy enough burden for our child, they often experience other traumas that seem to go unnoticed. My son had multiple seizures starting when he was twenty months and continuing until he was seven years old. He always went to hospital by ambulance because his seizures wouldn’t stop, going on for more than half an hour on occasions.

Medical Trauma

During his many hospital visits, including intensive care, he was poked and prodded, given a lumbar puncture, scans, injections, and drips. He would have his hands bound because he would pull the cannula out, then he used his teeth to pull it out. He was held down forcibly several times, kicking and screaming, while the nurse tried to get a blood sample to check the levels of his epilepsy medication.

He required dental procedures because the epilepsy medication ruined his teeth. He fell off his skateboard and knocked his front teeth out, requiring another visit to the dentist to pull them out when he was about 5 years old. Medical trauma is often ignored or underrated. It can be extremely traumatic for anyone, but especially for a small child who may not understand what's happening or why.

Being Bullied

In addition to medical trauma, our children are extremely vulnerable to being bullied. Some reports are as high as 98% for children with autism, which is more than any other kind of disability. Our children can be easy targets because of their inability to read and understand social cues, and then have reduced capacity for emotional self-regulation. It's easy for others to trigger them and stand back and watch the fallout. Then if our child lashes out, they're labelled a behavioural problem.

I was called to the school my son attended which was a "special school" for children with disabilities. He had been punched in the face by another student and had a split lip. When the school called, they told us not to worry, as he wasn't crying. My husband, bless him, said I should go to the school and pick our son up, as he would be traumatised. My husband was so right and insightful when I wasn't able to respond. This wasn't the first time my son had been assaulted.

In his communication book I would make note that my son had teeth marks on his arms or legs and other bruises. I feel so sad now that I didn't know how to respond or what to do at the time. After I collected my son from school that day, after I was made to wait outside the principal's office for over an hour, he never went back to school.

If that happened now, there's no way I'd sit patiently outside the principal's office waiting for someone to bring me my son. I would be demanding the doors be unlocked so I could get in and see him immediately!

I feel sad that I sat and waited for so long. The school completely ignored me when I arrived. Then when they did finally come and get me, I was made to give a report about the incident which took a long time as well. Then nothing more was done. It's horrendous that my son was treated like that. The awful assumption by the school that because he wasn't crying, he was OK was appalling to me, and now even more so. Thinking about polyvagal theory, he had probably gone to shutdown freeze mode because he was so terrified.

No Friends

The behaviours of our child often make him unpopular and can leave him with no friends or social support to buffer the cruelty of some children. The emotional abuse our children suffer at the hands of other children and adults, including teachers and therapists, maybe even relatives like a partner, grandparents, or other family members, is traumatic for them.

Sometimes, our children aren't the easiest to love. Their behaviours don't evoke warm fuzzy feelings often. People may even feel justified in punishing them in abusive ways, either verbally or physically. Sadly, children with autism are the most likely of any disability to be killed by their own parents. It can be hard to differentiate between their behaviours related to their autism and behaviours that may, instead, be their trauma reactions.

Vicarious Trauma

Concluding this chapter, we need to be aware that we may have experienced "vicarious trauma" through our child's experiences. If you recall, the definition and criteria for PTSD is hearing about or witnessing a traumatic event of someone you're close to. The bullying of our child can deeply affect us as well as him. It can be helpful to keep our own trauma reactions in mind when we're trying to deal with his trauma.

It can feel overwhelming because we're trying to "contain" and "hold" our child emotionally, calm ourselves to help him co-regulate, and then try to manage our own trauma responses to what they're experiencing while keeping ourselves contained and calm. It's really tough! Often, it doesn't just happen once or twice in our lives. It may be a situation that's repeated with some frequency as our child struggles with their behaviours and reactions with others. Be kind to yourself.

Questions for reflection.

1. Do you experience hypervigilance?
2. Describe what happens for you.
3. Do you experience depression?
4. What's that look like for you?
5. Has your child experienced trauma?
6. List some of the traumas your child has experienced.
7. How do you feel when you look at the list? Name an emotion or two if you can.
8. How do you feel about your child when you look at the list?
9. Might some of your child's behaviour be trying to tell you something?
10. What might your child be trying to tell you through their behaviour?
11. Might you have experienced some "vicarious trauma" through your child?

Chapter 12

HOW IS MY PAST AFFECTING ME?

Summary

Now you have a good grasp of what may be happening to you and why you feel the way you do. How do you bring about change for the benefit of yourself, your child with autism, your other children, your partner, and pretty much anyone else you have a relationship with? Be encouraged. There are things you can do that will bring more peace into your life.

Practice Conscious Awareness

Practicing conscious awareness might sound a bit “fluffy” and not all that helpful, but I assure you it’s a vital first step. When we have been experiencing trauma and aren’t able to calm ourselves, we can either react with anger and aggression (fight) or withdraw and dissociate (flight) when we mentally, physically, and emotionally check out.

We can become absent in our bodies. It could also look like running away and leaving the house or zoning out on a video game or some other digital oasis that asks nothing of us. When we're in a really traumatised state, we may not even be aware that we're reacting in any of these ways.

If we've never known anything different, maybe due to the way we were parented, it might seem normal. The way we've been parented has a significant effect on the development of our nervous system and how we relate to others in our relationships and as parents, how we relate to our children.

Please, allow me to caution you. The purpose of this next section is not to allow you or encourage you to blame your parents. I believe that Freud did mothers a huge disservice in blaming them for the problems a child has as a child and as an adult. My purpose is to help you to understand and generate compassion for those around you, which includes your parents. Your mother is likely to have had traumatic experiences too. She couldn't give you what she didn't have. Let's be kind, not judgmental.

Let's be kind, not judgmental.

Attachment Theory

Attachment theory is important because it will help you to understand your reactions and how you interpret the world and your relationships. Remember, polyvagal theory is about how safe we feel in certain situations. Attachment theory helps us understand when and why we feel safe or unsafe. Dan Siegal[1] suggests the attachment can be summarized by saying children need to feel safe, soothed, seen, and secure.

Keep in mind that, usually, no one is all one thing and none of the others. We usually use a bit of a few of the attachment styles. I encourage you to be brave as you read the following. It may be a bit confronting. You may feel sad, betrayed, thankful, angry, or relieved to name a few emotions you may experience.

The Four Attachment Styles Developed by John Bowlby.

The four attachment styles were first developed by John Bowlby.[2] His theories went largely unnoticed until more recent times when they've become foundational to many branches in psychology. The four styles are secure, anxious, avoidant, and disorganised.

Secure Attachment

Secure attachment happens when the primary caregiver, often the mother, is predictable, consistent, and trustworthy. We are attuned or in tune with our child and his physical and emotional needs and we respond to him in a positive way.

If our baby cries, we soothe him by picking him up, holding him, maybe rocking him, speaking to him in a higher-pitched voice, telling him it's alright, mummy's here, and, of course, if he's hungry, we feed him. This is what we aim to be as mothers. We don't need to be perfect because that's impossible. But we aim to be "good enough."

Repairing the Relationship

How much is "good enough." Edward Tronick suggests that even the best parents are only "attuned" 30% of the time. When something does go wrong, and there's a disconnection or rupture between us and our child, we make a repair to the relationship by reestablishing connection through maybe an apology, forgiveness, kindness, and warmth towards our child.

Sometimes, our children do something wrong, like breaking our favourite cup while they were trying to help wash up the dishes, and we need to forgive them. Or we may do something wrong and express anger or impatience when what they're needing or wanting is reasonable. We hurt our child's feelings. We can make a repair to the relationship.

As adults and parents, people who are securely attached can trust others and know that if they need help, someone will be there for them. They can maintain their unique identity and make their own decisions. They have autonomy to do what they think is best. They're responsive to their children. Securely attached parents will still struggle with their child with autism and his behaviours, but they may have a stronger social network to support them, and they may be less likely to take their child's behaviours to heart or the opinions of others about themselves or their child. They're less likely to be at risk of developing PTSD.

Anxious Attachment

Anxious attachment may also be called insecure, ambivalent, or preoccupied. This style of attachment occurs when the primary caregiver is inconsistent and unpredictable. We might feel cared for at some times, but other times we might have had the experience of being yelled at when we express our needs or rejected for needing or wanting something. We may struggle with self-doubt and self-criticism. It's hard to make decisions, and we may find we allow others to make decisions for us.

We might be described as "clingy" or "needy." We tend to be possessive in our relationships and experience jealousy if our partner, for example, wants to spend time with other friends. We try to keep them all to ourselves and can risk smothering them and driving them away. Then we experience rejection, the one thing we have feared most.

As a parent of a child with autism with behavioural challenges, raising a child with autism will present unique challenges for mothers who have a predominantly insecure attachment style. Being in a position of feeling very sensitive to rejection can create a world of pain for them as a mother.

We know that mothers in our tribe tend to experience a lot more rejection and isolation because of our child.

If we have insecure attachment, we’re going feel more like we’re the ones being rejected because of ourselves. When we’re rejected, it hurts regardless of our attachment style, but the intensity of the hurt is likely to be greater if we have an insecure attachment style.

If we weren’t self-critical enough before we had our child, we have so much more to hate ourselves for now! If we had self-doubt before we had our child, we have so much more to be doubtful about our capacity as a mother and a person now.

Whatever shortcomings and struggles we had before our child will be magnified as we continually fail to manage the behaviours of our child. We may feel rejected by our child, who doesn’t give us positive social feedback that we’re doing OK as a mother. We get minimal eye contact if any from them, they may look through us when they do look at us, they may scream at us or hit us, be verbally abusive towards us, be tactile defensive and never reach out to us for a cuddle or a snuggle, and we may be unable to comfort them in the ways we would our typical children. It can feel like full-blown rejection.

What emotions might that stir up in us towards our child, who so desperately needs us but pushes us away at the same time? We may be looking to our children to meet our needs, to love and nurture us, rather than the other way around. It's a genuine challenge to parent and feel good about ourselves when we have an anxious attachment from childhood.

Avoidant Attachment

The avoidant attachment style, also called insecure dismissive, is formed when our primary caregiver is distant, disengaged, or unavailable. Our needs to be seen, loved, understood, and protected were dismissed or ignored. As a result, we learned to take care of ourselves. We became self-reliant.

As adults, we may find ourselves pushing others away and appear cold or distant. We may have become dismissive of other people's feelings and needs, as we haven't had much experience with our needs being met or meeting the needs of others. It can be difficult to ask for what we want or need. It may mean we ignore our own emotions and feelings.

As a parent of a child with autism, we may struggle to reach out for support from people we know or professionals. Instead, we might try to solve all our problems ourselves. We may think, *If I just try harder, I can get this sorted myself.* Our children may find it difficult to get close to us and feel safe with us because we aren't giving him any feedback when we are tuned out.

We don't include our emotions and see less need for them because we may struggle to empathise with our child with autism or with our other children when they find life with their sibling difficult. We don't give them a soft place to land. We may find any of our children needy, especially our one with autism, and feel resentment toward him.

Disorganised Attachment

The disorganised attachment style occurs when a child finds their primary caregiver frightening or terrifying. The caregiver is unpredictable and reactive, laughing one moment at a behaviour and exploding with anger at the same behaviour the next. This leaves us with no organised and reliable way of getting our needs met.

One of our most basic needs is to feel safe, but we didn't feel safe growing up. We may pull away when someone comes to us emotionally or physically, but pursue them when they don't. This type of behaviour can be scary for a partner but also for our own children because we are reactive and unpredictable.

As a mother of a child with autism who may appear to have erratic behaviours, we can be very reactive to the behavioural challenges we face with him. We may find our child to be frightening and reminiscent of our childhood. This may lead us to pull away or blow up at him. Neither reactions are helpful to either of us.

We have learned that the world is a dangerous place. How might that affect us as a parent of a child who runs away all the time? Our worry will be intensified. We'll be more sensitive to the risks our child takes. Our already present feelings of helplessness or hopelessness and despair may be intensified as we observe our child's behaviours and our inability to manage them.

If we have grown up with an abuser, we may find ourselves putting some of those characteristics onto our child. At times, it's easy to see our child as being a narcissistic abuser. He only ever thinks of himself, he tantrums and manipulates to get what he wants through behaviours, he may be violent towards himself or others, verbally abusive or destructive towards property, and show zero empathy for how anyone around him may be feeling.

Sometimes, no matter what you do to try to please or appease him, it's just never right, and he melts down anyway. The behaviours we are exposed to by our children wouldn't be tolerated by anyone else. It can gnaw away at our self-worth when we're treated in an abusive way. Although we may understand that our child can't help his behaviour, it doesn't make it any easier for us or the rest of the family to live with. It can feel hurtful emotionally as well as physically hurtful.

Questions for reflection.

1. How aware are you of what you're feeling when you're upset or calm?
2. What's your predominant attachment style?

3. What behaviours do you do that you think might be based on your attachment style?
4. How does your attachment style influence your parenting style?
5. Are there things you might like to change? What would they be?
6. What's one thing you can work on changing and what will you do differently?
7. Do you understand that change takes time and practice? You're still going to have times when you react in the old way, and that's OK.
8. Focus on when you get it right rather than when you slip up with an old pattern. What have you done well this week?

Chapter 13

HEALING OUR ATTACHMENT WOUNDS

Summary

We all have attachment wounds but we can heal them. This chapter is one way we can do that.

Mourn

Now we have become aware of our predominant attachment style or styles, what can we do about it? How can we heal those wounds from so long ago? We cannot have our childhood over again with different parents and experiences. Would we want to when our experiences make us who we are and are so much a part of us? The first thing to do is to mourn and grieve. If you're busy right now and not in a private place, I suggest you wait to do the next exercise until you're home and in a quiet place.

Many of us have had less than optimal upbringings. We know that no parent is perfect. Although most parents do their best, some parents are better than others, and we miss out or are broken and wounded as we emerge into adult life. With what you know now, think about your mother. What needs do you have that went unmet by her?

I urge you to keep in mind that your mother may have also emerged into adult life broken and wounded as well. She may have had depression and, through no choice of her own, was unresponsive to you. She simply didn't have the capacity to give you what you needed. Sit with those feelings of loss briefly. No need to drown here. Just touch those emotions of loss if you're able to. Hold those emotions lightly. Tolerate them briefly.

Mothering Your Inner Child

Next, see yourself as that little girl. You're going to nurture your younger self. Now see yourself as the adult woman you are now, filled with compassion for that little girl, wanting to reach out to her and meet those needs for her. What will you say to her?

Imagine your younger self in the arms of your present self. Wrap your arms around yourself, squeeze yourself in a hug, rock if you want, to comfort and soothe your younger self. Tell her what she longed to hear as a child. Keep breathing.

"Thank you, little one, for doing the best you could. I understand. But I'm here now and I'll take care of you. There's no need to carry those burdens anymore." Put down your shame, bitterness, and anger, and replace it with kindness, empathy, and love for that dear little girl, who is you. Now come back to me.

Grounding (Do not skip this step even if it feels stupid)

Look around for five things you can see, four things you can hear and three things you can touch. Feel yourself in your chair, feel your feet on the ground and dig your heels into the ground literally. Hopefully, now you're grounded and back in your body. Keep breathing slowly. If you're panting, slow down.

This exercise helps you mother yourself. All of us who are dismissive-avoidant will love that! We can do it ourselves. I recommend you do this in small bite-sized pieces. You cannot eat the whole elephant at once. Be gentle and respectful towards yourself. Be compassionate towards your younger and present self. This takes practice. This takes time. Be patient. If this is overwhelming for you, consider getting a therapist to help and support you.

It's important to do the painful work of reviewing our childhood attachment style to help ourselves and our children, so we don't end up passing our trauma along without intending to. It also helps us to think in-depth about how we want to parent our child with autism and our other children. Their needs will likely be different. We cannot give from an empty well. I encourage you to take some time to fill yourself and work on your healing a bit at a time. To do that, we need to become aware of what behaviours we're doing, and what feelings we're having. It can be really hard at first if we've become numb, but with practice, it's possible to become more aware of ourselves.

With awareness, we can work towards change. We're busy, stressed, maybe depressed and anxious, maybe having some symptoms of PTSD. What on earth am I doing even suggesting this? I get it. It can feel overwhelming. Like I said before, you're going to nibble away at this rather than eating the whole elephant. This is a journey, not necessarily a destination. Get support from a therapist if you need to.

> With awareness, we can work towards change.

Questions for reflection.

1. What needs do you have that went unmet by your mother?
2. What needs do you think your mother had that went unmet?
3. How do you think your mother's unmet needs affected her and, therefore, you?
4. What would you as an adult now like to say to your younger self?

5. What emotions have you experienced through this chapter? Can you name them?
6. Please take a moment to do the grounding exercises if you skipped them before or you’re feeling a lot of emotions now and seem to be shutting down.
7. Can your grown-up self today love and comfort that little girl you were?
8. What burdens are going to lay down from this day forward?

Chapter 14

DEVELOP COMPASSION FOR YOURSELF

Summary

One way to bring change to your life is to develop a new mindset. We know that mothers of children with autism can feel less in control in their lives than other mothers. At times, we may feel incompetent, we may be isolated, and we may feel burned out. The constant interruptions to head off or repair after a disaster can scramble our brains to the point where we can longer think straight at times.

In this state, it can be hard to imagine developing a different mindset. This where we need to use our imaginations again to help us change our perceptions of our situation. We may be able to make some gains in changing our child's behaviours, but we can change ourselves for certain, as much as we are willing to.

One way to bring change to your life is to
develop a new mindset.
We need a new mindset to change our
perspectives and perceptions.

Cultivate Self-Compassion by Developing a Compassionate Mindset

Self-compassion might be a tough one for some of us when we've been so hard on ourselves. But this is an essential element of bringing change to our lives. We've got a really tough job parenting, so give yourself a break and be kind to yourself. Often, we might find that we say the most horrible things to ourselves that we wouldn't dream of saying to someone else. Our self-talk is overly critical and harsh, completely lacking in compassion.

What would a good friend say to you about you, or what would you say to a friend who was in your situation? I imagine you'd be understanding, empathic, and compassionate towards them. You're not going to tell them what a loser they are, they should try harder, stop complaining, or suck it up.

To a friend in our position, we would have empathy and understanding towards them. We wouldn't be condemning them, calling them names, and telling them to toughen up. How could we! We're already about as tough as any mother can get! We don't need more toughening up.

Some of the words used to describe self-compassion include nurturing and cultivating. This sounds like growing a beautiful garden. We nurture our seedlings; we cultivate the ground to make it the best it can be for the healthy growth of our plants. We don't plant a seed, dig it up, and poop on it, then watch it die. Don't do that with your seeds of self-compassion either!

You're going to plant a seed of self-compassion into your heart and nurture it as you would a seedling. You'll water it daily, feed it, and shelter it from the elements until it's strong enough to be planted out in the garden. Think of your babies. How do you nurture them? Show yourself the same kindness. This might be a new thing for you, so start small. Appreciate something about yourself. Hey, you might have managed to take a shower today! For some of us, that's an achievement.

Be proud of yourself. Kristin Neff suggests giving yourself unconditional acceptance without judging your shortcomings so harshly.[1] We don't expect our friends to be perfect, yet we may expect that of ourselves. Treat yourself like your best friend. You're going to make mistakes because you're human.

You're allowed to make mistakes, and be kind to yourself about it. Making a mistake doesn't make us a bad person; it makes us human like everyone else. We aren't alone in our struggles. We're part of a tribe of autism mums who get each other and know how it feels. Our similar struggles unite us! You're not alone in your struggles.

Our similar struggles unite us! You're not alone.

Ask for What You Want and Need.

Sometimes, we can be so distressed we don't even know what we want or need, so we carry on, having our own meltdowns when we don't get it, whatever it might be. Knowing what we want and need and being able to ask for it is a form of self-compassion.

If we've been busy hating ourselves, it can be easy to think we don't deserve anything. We can feel this way, especially if we have depression and feel unworthy of having our wants and needs met. This isn't true. Our needs may be physical or emotional.

When we're depressed, stressed, and anxious, we may find it difficult to identify what we need. If we don't, how will we be able to communicate to those around us who may be wanting to help and support us? I can hear you right now objecting: "I don't have time for more fluff." This isn't fluff; it's vital if you're going to make it through the marathon that is parenting your child with autism.

The Five Love Languages.

When our needs go unmet, we can find ourselves blowing up more than we would like to. I encourage you to think about what you need. What's your love language? There are five love languages: physical touch, gift-giving, acts of service, quality time, and words of affirmation.[2] Gary Chapman has written many books about this and offers a free quiz on the website if you're not sure.

Do you need more hugs, more help around the house, time alone with your partner or friends, or more encouragement? All of them are good, but which one really speaks to you. You're busy, so knowing which one it is and doing that one gives you a big bang for your buck! It fills up your love tank to help you keep going. Do this with your partner and even your other children. Find out what they need and get the best bang for your buck.

Let the people around you know what you need by asking straight out. You might be thinking, *But they should know!* I hear this all the time in marriage counselling, and I want to say right now, stop it! Your partner cannot read your mind. We wish they could, but they can't. Don't be subtle with your partner. He may know he's done "something" wrong and may apologise, but he may not be clear about what your problem is. Stop hinting and ask for what you want and need!

Just one caution - ask nicely. Don't say, "You never help me! I'm always doing everything. Why don't you ever help?" That's accusing and not very motivating for your partner. It might well be true, but asking like this won't get you the result you need and want.

You can say, “Hey darl, I could really use your help with this (be specific). Could you please stack the dishwasher?” You can argue that you shouldn’t have to ask. OK, I hear you. But you do need to ask. I’ll say it again; stop being so stubborn and just ask.

Stop hinting and ask for what you want and need.

What’s Your Personality Type?

What’s your personality type? Are you an introvert or an extrovert for example? You can find many Myers-Briggs personality quizzes available online if you’re not sure what yours is.

Extroverts

If you’re an extrovert, you need time with friends, going out and having fun. It’s not just that you like that; you actually need it. Having a child with autism can seriously reduce how you meet this need. It might be hard to go out now, and no one wants to babysit for you. Your list of fun friends may have been reduced. Feeling isolated is like a slow death for you if you’re an extrovert. Ask for what you need. Find some childcare somehow, and get yourself out of the house to have some fun with friends. I know this is easy to say and hard to do, but try to find a way to meet this compelling need you have. It might just be twice a year, but ask for the help you need to make this happen.

Introvert

What if you're an introvert and someone who likes to be at home and do quiet activities like reflecting and overthinking? You might be the person who wants to be invited to events, but be very glad when they get cancelled and you don't have to go. Introverts need time alone and some quiet time. This is a need, not just a want.

Without some quiet time alone, introverts can become even more stressed. They need time for calming, and some peace and quiet. I get that this can be difficult to achieve, but get creative and find a way to give yourself some quiet time.

It might be reading a book in bed before you go to sleep or journaling, or having a glass of whine—oops I meant wine—watching a movie after the children go to bed. It won't be easy, but it's possible to carve out for yourself some quiet moments. When you do, be intentional about taking a deep breath and relaxing physically and mentally. Ask for help to make this happen.

Asking for Services.

Less close to home, you may need to develop some assertiveness. When mothering a child with autism, you have to do things you've never done before. You may feel like a little mouse, but you're going to have to find your voice, your inner lion, and roar, sometimes, to get what you need for your child. It might be at school or at therapy. You know your child best, and you have a right, even a mandate, to ask or even demand the services your child needs. Wake up the warrior-hero that's inside you. Claudia Taboada has written a great book, *Burnout to Unstoppable*, that can help you further. Check the resources at the back of the book.

It can be scary in the beginning, but with practice, roaring will become easier. Roaring is not being rude or disrespectful to the person you're asking. No shouting is required. My experience has been that once I began to respect myself and stand tall, rather than have my tail between my legs, my voice was heard. I began to see myself as the team leader and others were on my team for my son, but I was in charge.

Previously, I had felt like Oliver asking for more gruel, "Please sir, I want some more." For the sake of my son, I became brave. You can too. Sometimes, if I haven't been heard asking nicely, I may send a draft of a letter to the person who is obstructing me or not caring, and letting them know that this is the letter I will be sending to their superior. I usually get a phone call very quickly, telling me about some action they will be taking.

Rely on other people's authority if you're not being taken seriously. You don't need to shout or be abusive. Just follow the process. There are laws in place at least in Australia, where carers must be treated with respect, listened to, and taken seriously. Use the authority of the law that has been given to you and be confident that you have the right to assert yourself and the needs of your child. Be that squeaky wheel and get that oil!

You may feel like a little mouse, but you're going to have to find your voice, your inner lion, and roar.

Compassion Toward Our Child

Another area of compassion we can develop is towards our child. Our child does the worst things, frequently. His behaviours may just tip us over the edge into a meltdown of our own on a really hard day. When we feel frustrated or overwhelmed or angry, it can be almost impossible to empathise or feel compassion towards the source of those negative feelings.

Take a breath. Calm yourself and try to put yourself in your child's shoes. How might he be feeling? Is he scared, angry, or frustrated about something? It doesn't have to make sense why he's upset. My son can get upset because it's not Tuesday or it's raining. I can't do anything about either of those!

But, can I imagine what it might feel like to not know what day is, and therefore not know what's going to happen next? What would it feel like to be so certain today is supposed to be Tuesday, but everyone around keeps telling you it's only Monday? Tuesday is tomorrow. It doesn't help. "Why won't anyone listen to me because it's Tuesday?"

"Maybe I don't like something that happens on Monday, but I don't have the words to tell you. Maybe I hate art because I'm going to have to touch squishy stuff. Maybe we always have peas on Monday and I hate peas. Maybe Monday is the day someone bullied me a year ago and I can still remember it. It still upsets me and I don't know what to do with those feelings."

There are a million different scenarios about why our children melt down that may seem irrational and plain annoying to us. You probably have a few of your own. When we're in a hurry to get out the door, it can be the last straw to have our child behave in a way that *appears* defiant. But is it defiant or a cry for help and understanding? It can be hard to tell but we can consider it at least.

It's certainly annoying and upsetting for us when we are trying to keep life going for the whole family, and there's this one spanner in the works almost every time! Can we for a moment imagine what it might feel like for our child? First, he has the primary problem, that it's not Tuesday. But then the situation escalates and another problem evolves, as everyone gets mad at him and expresses their frustration, and he doesn't understand why.

It can be extremely difficult to put ourselves in our child's shoes in this kind of situation. We're upset, they're upset and so is the rest of the family. We can sometimes find ourselves directing our anger and frustration towards our child. But if we can try to take a deep breath, and imagine what he's experiencing and what his behaviour is trying to tell us, we can possibly turn the situation around, at least a bit.

If we can do this, we model it and show the rest of the family how we're going to react with intention in these frequent situations. With practice, the resolution stage can speed up for you and him. It's not going to be easy or fast, but it might be possible. Your child is going to continue to get upset, maybe for the rest of his life, about "stuff." The question is, are you? Or are you going to learn to regulate your own nervous system first and lead the way towards change?

Questions for reflection

1. Have you been able to use your imagination? Do you need more practice?
2. What would a good friend say to you about yourself?
3. What condemnation do you heap on yourself?
4. Are you willing to stop doing that and become your own best friend?
5. How can you change the narrative of what you say to yourself to be more compassionate and nurturing? Write some things down. Do it! Right now!
6. What do you need?
7. How are you going to ask for what you need?
8. Who are you going to ask first?
9. What's your love language? Go here to find out: https://www.5lovelanguages.com/quizzes/

10. What's your personality type?
11. What services do you need for your child but have been afraid to pursue and ask for?
12. Which one will you ask for first and what will you say?
13. Take some action on at least one of these ideas today.

Chapter 15

HOW DO YOU FEEL ABOUT YOUR CHILD?

Summary

How we feel about our child in the back or front of our minds will influence our perception of our child and how we feel about ourselves as his mother.

I'm going to touch on a sensitive subject here. How do you feel about your child?

Did you want this pregnancy? Was this child a surprise that you grew to love when you were carrying him, and now you've got to know him, feel resentment towards? Do you regret having this child? Do you feel disappointed with how this child has turned out, having autism and whatever other alphabet soup diagnosis has made parenting him challenging for you? Do you blame him for having autism? Do you blame someone else?

Do you blame yourself? What if you did this or that when you were pregnant? Could this have turned out differently, less difficult, less expensive? Has having this child stolen away some of your hopes and dreams? Maybe you can’t work anymore. You might have had a job you loved and were good at and you can no longer work because you have to stay home and care for your child.

Maybe you were going to go back to study and now you can’t. Maybe you were going to spend your money differently, enjoying yourself, rather than spending it on therapy. Had you gone back to work, you would have more money, but now you’re living on one income or less because of your child with autism.

You may resent the worry and burden of wondering what will happen to him as you age and die. Who will care for him? And you worry about him. What have you lost or given up because of your child? What and who have you lost because of him?

It’s OK to feel sad and mourn the losses your child has brought into your life. It doesn’t make you a bad person, it makes you human. We know that most tribe members have lost or given up something or someone. Losses hurt. Some hurt very deeply.

We may experience rejection from people we never expected to. We may lose family or friends. We may lose opportunities and work. Many of our tribe say they're worse off financially than they would have been without their child with autism. Some of our hopes and dreams about what motherhood was going to be like have withered and died. It hurts.

Sometimes, we can project all that loss and associated anger and frustration onto our child. He comes to embody everything that's gone wrong in our lives and we feel negatively towards him. He does behaviours that make it hard to feel love towards him at times.

We know we love him because we make the decision to do so, and it's what's expected of mothers. But our children sure don't make it easy sometimes! To be blunt, it can be hard to love someone who has ruined your life as you knew it.

To be blunt, it can be hard to love someone who has ruined your life as you knew it.

We can feel a vast array of emotions related to our child with autism and the losses we have experienced as a result. It's OK to feel sad about some things that will be either delayed or maybe never happen. Your child may not marry and give you grandchildren. He may not make good friends, play team sports, or travel or live independently. It's OK to mourn these losses as well.

We can acknowledge that our lives will never be the same again! Maybe we want our pre-autism life back, and that's just not going to happen. It's OK to acknowledge that and feel sad. But don't set up house and live there!

Acknowledge your losses, real and imagined. Acknowledge that life has changed and will never be the same again. Maybe your imaginings weren't realistic in the first place. But whatever they were, they're gone now.

I'm not going to tell you to pack up and move to "Holland" either and pretend like everything is OK. It's not. What I am suggesting is to allow all feelings, negative and positive. Acknowledge and welcome them all, but try not to let the negative ones rule over you or hold you captive. Bring out your compassion in these moments, for yourself and for your child.

Your child didn't choose to live with autism any more than you did. You didn't cause it and neither did he. Get on the same side as your child, not on opposite sides of blaming him or yourself for the losses and disappointments you have and will experience in the future most likely.

Forgive yourself if you have been blaming yourself or chastising yourself for feeling sorry for yourself. Forgive your child if you need to. Set yourself and him emotionally free, and make room for compassion for yourself and him. You're both doing the best you can.

How Much Should I Have to Adapt?

If you're anything like me, you may say to yourself at times, "I shouldn't have to." In a perfect world, you wouldn't have to. Everything would be as we like it. But life and the world aren't like that, for me anyway.

Sometimes, I feel like I've bent myself so far out of shape to accommodate my son, I should look like a paperclip. It's not fair! I cry inwardly. This is ***** ridiculous, and it probably would be if he didn't have autism. But he does. It's not fair. This is where we need to bring our compassion for our child to the fore.

My son over the last few years has found it extremely difficult to leave his washing on the line. He obsesses over it, and sneaks out to the washing line, smuggling it in when we're not looking, folds it up and puts it away wet! I forget and may notice later when he is wearing a t-shirt that smells "funky."

Trying to find a way to get his washing done in peace was becoming impossible and I was getting upset about it frequently. I could do with taking my own advice and calming down!! I found it infuriating. We would try to get his washing done when he was out, but sometimes it wouldn't be quite dry by the time he got home and the scenario would start over again.

He didn't mind if his washing went in the dryer and he would wait for it to beep and happily put it away. But, when it was 40 degrees Celsius, I didn't want the dryer on in the house. The clothes would dry quicker on the line anyway. So, I continued to insist on doing things my way.

Eventually, I realised I was being an idiot! We decided to allow the dryer to be used for everything that was his. He also began taking our clothes off the line wet too, so we tried to do our washing when he's out. We bought him bigger shirts that if they shrank in the dryer they would still fit. I stopped insisting that certain items couldn't go in the dryer. We found ways around it.

It may seem so silly and petty, but it had become a real problem in our house. Logic had nothing to do with it; it was an obsession. You can't always negotiate with obsessions. I needed to adapt and change and find a way to make this work for our son. I was being rigid when I really didn't need to be. Yes, we'll use more electricity running the dryer and the air conditioner on hot days, and his clothes will wear out faster and may shrink. But was that really so bad? No, it wasn't. I needed to let go and be flexible when he couldn't.

What about you? How do you weigh up what needs to be done and what can be done differently? Sure, I hear you. It's not fair. It may be stupid. But can we find ways to use our compassion for our child and ourselves, and give a bit more flexibility, to bring a bit more peace? This may mean we need to figure out how to make it fair for our other children too.

Maybe we can give our other children more flexibility too? He's having a tough time too. It can be really tough to keep everything the same and equal for all the children when you have one child who is not on the same page or even the same planet.

> Can we find ways to use our compassion for our child and ourselves, and allow a bit more flexibility, to bring a bit more peace?

Questions for reflection

1. How do you feel about your child? Name some honest emotions, positive and negative.
2. Are you able to feel empathy and compassion for your child?
3. What's a good example of your empathy and compassion?
4. What losses have you experienced because of your child's autism?
5. What adaptations have you had to make to accommodate your child's needs and behaviours?
6. How do you feel about making those adaptations?
7. How flexible or rigid are you with your child's behaviours and obsessions?
8. Are there situations when it could help your child and the rest of the family to be more flexible or more rigid? Name one or two examples.

Chapter 16

DEVELOP COMPASSION TOWARD OTHERS

Summary

Developing compassion for others is a way to help us manage our external world and tolerate and reframe the criticisms and interference from others.

Responding to “That” Person

Developing compassion towards others might seem like a strange thing to suggest. Maybe it is. As mothers of a child who looks very naughty and disobedient, we may receive unwelcome interventions from the general public, who, without being asked, throw in their two cents worth to help with our parenting because, obviously, we’re hopeless and stupid. I’ve had this experience. Maybe you have too.

I've wondered, *Why don't they mind their own business!* I'm having a "fight" response to defend myself. Alternatively, I might feel myself wither and become small. I may not say anything, or I may even say, "Thank you," and try to apologetically explain the situation. Then I may scurry away feeling ashamed and small. I'm having a "flight" or "play dead" response.

Why do people interfere? Maybe they think they can help or offer support or maybe they're just busybodies. Maybe they think you need to be told to give your child a good hard smack to help them snap out of it. Maybe they feel they need to tell you how useless you look. Whatever their reason, I've never found it helpful or supportive. I usually feel angry and outraged, even if I don't show it on the outside.

Their unsolicited input may pressure us into treating our child differently so we appear to be doing something. When we want to look like a good parent and feel like we need to look like we're doing something, we can be coerced into dealing with our child differently than what we already know works.

We may feel obliged to shout at our child, grab them, or drag them away from the situation. We may get our defences up and return an aggressive response to the interferer, which will further convince them that "some people really shouldn't have children."

Why would I even consider suggesting we have compassion for these people who make our lives hard? Think about it.

What kind of person interferes in things that are none of their business? Maybe a busybody? How popular are busybodies usually? My estimation is that they’re not popular at all. People tolerate them but don’t trust or like them. We don’t know how they ended up this way, and that’s not our problem or our business.

The kind of person who hands out advice to strangers is probably lonely. If they’re bossy and a know-it-all, they probably don’t have a lot of genuine friends who will put up with their manner. They behave rudely, which they just showed you. They have poor social skills and lack the capacity for empathy. If they could empathise, they wouldn’t be giving you advice or judgmental stares and glances.

Maybe they’re angry and disappointed with their life and are looking for someone to let off some steam on? They don’t know you. They can get mad at you and not have to face any consequences. They’ll walk away, thinking they did some good.

When they get home or sit next to another stranger on the bus, they may tell them what a good job they did straightening you out, and letting you know they disapprove. They will justify their rudeness to themselves and others, anyone who will listen perhaps.

It’s not wrong to feel angry towards these people who step in. They’re being rude and making an already difficult situation harder. But, the kind of person who would do this lacks empathy. They lack the capacity to imagine how you or your child feel in the situation. Use your imagination to think about what their life might be like? Who wants to be around them? Probably not many people. They lack compassion and understanding of their fellow human beings. We ought to feel compassion for them.

They don't understand how to be fully human. It doesn't mean we like or accept what they do. But it does mean that we don't need to carry any feelings or get defensive towards them. They don't need or deserve an explanation of any kind from us. You can let go of the contempt you feel towards them.

They're a small person in a big world, trying to look bigger and more important than they are. That's sad, and for that reason, we can feel compassion for them for their ignorance and smallness, in the midst of feeling annoyed or angry with them.

We Forgive for Our Sake

We feel compassion for them for our sake, not theirs. We forgive them for being insensitive for our sake, not theirs. We owe them nothing, and, as such, we don't allow them to plant negative emotional seeds that will grow when our anger nurtures them. That hurts us! We have enough burdens to carry. Let's put this one down.

Although it's changing, many people are ignorant about autism and what it looks like. Although autism has common features outlined in the *DSM-5*, each child is different. Mine son wants it to be Tuesday, and yours may want it to be red, whatever it is. Mine cuts the labels out of his clothes, often taking a chunk of the new shirt with it! Yours might insist on wearing his clothes inside out to avoid the seams. Our children may have similar issues but express them in different ways.

To people who don't understand our kids, these things are just ridiculous! Others may judge us, and tell us to make our kids toughen up. They're already tough because they got this far facing incredible obstacles we may never fully understand. What might it feel like if the seams in our undies felt like razor blades? Wouldn't we want to wear them inside out too?

We can't expect people not in our tribe to understand. If others choose to feel judgment and contempt towards us, there's nothing we can do about it. We'll be judged and we need to make peace with that.

Do We Educate the Public?

One thing I've struggled with at times, is how much of educating the non-autism world is my responsibility? Do I really have to have a teaching conversation with non-tribe members all the time? Maybe some people will think I'm just making excuses for my son's behaviour. I can't control what they think, and it's good to accept that.

It's not our job to try to change other people's minds about us or our child. Sometimes, it can be good to give a bit of education about autism and your child in particular if the circumstances allow for it and if it's going to be helpful in the future.

If we have the energy and the situation, we can educate others, to help make the world a better place for our children, one person at a time. But we don't have to carry the weight of the world on our shoulders and educate everyone around us about autism. If people are interested, they can ask you or search online for answers. People who care will ask. If they're not asking, then you don't have to be obliged to explain or educate them. But you can if you want to.

If we have the energy and the situation, we can educate others, to help make the world a better place for our children, one person at a time.

Questions for reflection

1. Can you think of a time when someone interfered in an unhelpful way with your child's behaviours?
2. How did you feel at the time?
3. How do you feel about it now?
4. Is there something you want to change about how you feel about that situation? What?

5. Are you able to feel compassion for them and forgive them for your own sake? Why or why not?
6. How do you react to unwanted advice about your child? Do you try to explain, apologise, or educate them? Maybe you do something else?
7. Do you want to change your responses to these people? Why or why not?

Here's some further inspiration from Theodore Roosevelt to help you cope with the critics.

> "It is not the critic who counts; not the man who points out how the strong man stumbles, or where the doer of deeds could have done them better. The credit belongs to the man who is actually in the arena, whose face is marred by dust and sweat and blood; who strives valiantly; who errs, who comes short again and again, because there is no effort without error and shortcoming; but who does actually strive to do the deeds; who knows great enthusiasms, the great devotions; who spends himself in a worthy cause; who at the best knows in the end the triumph of high achievement, and who at the worst, if he fails, at least fails while daring greatly, so that his place shall never be with those cold and timid souls who neither know victory nor defeat."

Chapter 17

CONCLUSION

It is my deepest wish that you have found this book a comfort and encouragement as you mother your child with autism. We face challenges unlike those of any other group of parents, including other parents who have children with disabilities. Our children do dangerous and scary things frequently. Their relentless behaviours mess with our mental, physical, and emotional health. It is common that we'll be responsible for caring for our children for the rest of our lives, or the rest of theirs if they die first from an accident or suicide. The outlook can be quite grim.

While this book takes a realistic look at what we face as mothers of children with autism, I also want to bring you hope. It can feel like we're going down with the good ship autism, but we don't have to. I'm hoping this book will be a life saver for you. Sure, I'm not claiming I can solve all your problems. But what I am saying is that there is hope and a different way to see the world and your situation and a different way to respond to the challenges we face.

Stephen Porges' Polyvagal theory has been around since the 1990s but seems to have gained more prominence recently. It has been life changing for me in helping me understand myself and others in a new and helpful way. The theory also offers us a way to change our life by changing our nervous system and our brain. Some of the negative consequences and risks we face as mothers of children with autism can be reduced and managed by understanding and changing our nervous systems.

Staying calm seems a ridiculous suggestion in light of what we know about mothering our child with autism. It may seem impossible, but it isn't. I'm not saying it's easy, but I am saying it's possible, and I believe you can do it!

Finally, this book is not intended to replace therapy. I encourage you, if you need professional support for anything that has been covered in this book, to please reach out. There's no shame in asking for help. Sometimes, we need to be brave a little bit longer, and ask for the help and support we need.

You're a good enough autism mum, and now, you can be even better with the new insights and understandings you've gained from this book.

ADDITIONAL RESOURCES

Burnout to Unstoppable by Claudia Taboada.

Find it here: https://www.amazon.com/gp/product/B084CWD4W1/ref=dbs_a_def_rwt_bibl_vppi_i0

This book is also written by a mother of a child with autism. It's very down to earth and gives practical suggestions on how to manage burnout.

A Drink Called Mindfulness by Erin Edwards.

Find it here: https://www.amazon.com/gp/product/B084CWD4W1/ref=dbs_a_def_rwt_bibl_vppi_i0

This book is how to get started using mindfulness especially if you don't think mindfulness is for you!

Raising an Emotionally Intelligent Child by John Gottman PhD and Daniel Goleman

YouTube links I find useful

Polyvagal Theory Explanation

https://www.youtube.com/watch?v=br8-qebjIgs

Elmo, Belly Breath

https://www.youtube.com/watch?v=_mZbzDOpylA&t=47s

Ellie Blake, Breathing to Calm the Nervous System

A great description of what happens to our nervous system as we breathe and relax.

https://www.youtube.com/watch?v=5gDfmBAh3ww

The Holistic Psychologist

This YouTube channel has many helpful video explanations about the nervous system, trauma, and healing.

https://www.youtube.com/channel/UCtEWTaMjqOH8J1Gy06Ey0Yg

Donald Winnicott's Radio Program Recordings (worth a listen)

https://www.oxfordclinicalpsych.com/page/609/the-ordinary-devoted-mother-and-her-children-parents-and-children-bbc-196062;jsessionid=5C3C3569A0B3F1BB8EADBC7A311A34B7

Resources for Carers in Australia

https://www.carersaustralia.com.au/

SUMMARY OF THE MAIN FINDINGS OF MY RESEARCH

An Investigation of Stress and Resilience in Mothers of Children With Autism Spectrum Disorder

Link to complete research paper:
www.feelhappynow.com.au/research

Abstract

Children with autism spectrum disorder (ASD) present unique challenges for their caregivers, which often includes maladaptive behaviours that may range from annoying to deadly (Obeid & Daou, 2015). Recently, the nature of stress experienced by some mothers of children with ASD has been conceptualised using a trauma framework (Stewart, Knight, McGillivray, Forbes, & Austin, 2017). Australian mothers (*n= 220*) of children with ASD aged between 4–16 years, completed an online survey inquiring into their experiences of trauma, the behaviours of their child, their

level of aggravation in parenting, resilient coping, and post-traumatic stress disorder (PTSD) symptomology. A mediation moderation path model was used to determine whether the challenging behaviours of the child with ASD or previous traumatic experiences of the mother influenced aggravation in parenting and PTSD symptomology in mothers and whether the outcome of PTSD may be moderated by the resilient coping of the mother. This study found that the challenging behaviours of the child with ASD were associated with increased aggravation in parenting and PTSD symptoms severe enough to warrant a provisional diagnosis of PTSD for almost a third of participants. Previous traumatic events did not influence the model. The relationship between aggravation in parenting and PTSD was not moderated by the resilient coping of mothers. Aggravation in parenting and PTSD are noted in the literature to have a negative effect on a mother's capacity to parent, suggesting mothers of children with ASD should be screened for PTSD and offered supports addressing their level of trauma in order to mitigate the potential impact of their child's behaviour on their mental health.

Main Findings

- 43.64% of mothers reported being unable to work due to caring for their child. Only 15.45% reported working full-time.

- 78.18% of mothers reported being in a relationship with a partner.

- 55% were educated to bachelor degree level or higher.
- 72.73% of mothers reported caring for one child with autism and 21.36% reported caring for two children with autism.
- 91.82% of mothers reported high levels of aggravation in parenting.
- 68.64% of mothers reported low levels of resilient coping.
- 31.36% of mothers reported meeting the criteria for a provisional diagnosis of PTSD.

The statistical model showed that the challenging behaviours of the child with autism directly influenced the level of aggravation in parenting, which influenced the level of PTSD experienced by mothers.

Pre-trauma was an insignificant variable, and did not influence the outcome of PTSD (or make it worse in other words). We were surprised by this result because we thought if a mother had other traumas prior to having her child with autism, she would be more likely to experience PTSD. This was not the case in this model.

Resilience of mothers was included in the statistical model to determine if it moderated PTSD. It did not influence the outcome of PTSD. This means that we tested to see if resilient coping in mothers affected the outcome of PTSD, so that the more resilient coping skills a mother had, the less likely she was to have PTSD. We were surprised that it made no difference to the model.

The Future

What my research and the research of a few others has shown is that mothers of children with autism could benefit from being screened for PTSD. Practitioners may need to consider the mental health of the mother when interacting with the child with autism. Mothers of children with autism may need more support and respite to manage their stress and mental health to be able to care effectively for their child with autism and their other children should they have any.

It would be interesting to know how parenting a child with autism affects fathers. At present there is very little data available to draw from. It would also be interested in mothers of children aged over 16 years, to see if they adapted to life after many years and recovered, or if they recovered after their child moved out. Presently this is unknown.

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"When the student is ready, the teacher will appear.
When the student is truly ready, the teacher will
disappear."
— Lao Tzu quote in Tao Te Ching

"If you want to go fast, go alone. If you want to go
far, go together."
— African Proverb

I have had many teachers appear throughout my life. Nobody arrives at a new destination without the help and support of others who come into our lives at just the right time—when we are ready. Below are a few of the exceptional people who helped me along in this part of my journey of life.

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ABOUT THE AUTHOR

Liz holds an honours and master's degree in psychology, has published research, and is a registered, practicing psychologist. Her most recent ground-breaking research discovered that a third of mothers of children with autism have posttraumatic stress disorder (PTSD) due to the challenging behaviours of their child. This is close to her heart because she is the mother of an adult son who has autism and an intellectual disability. She has been passionate about reaching out to her tribe of autism mums and helping them understand and overcome some of the common struggles they face, using candid examples from her own experiences.

Liz enjoys walking down by the local creek near her home and observing the wildlife. She lives in Western Australia and has been married to her soulmate Paul for 35 years.

Visit her website at: www.feelhappynow.com.au

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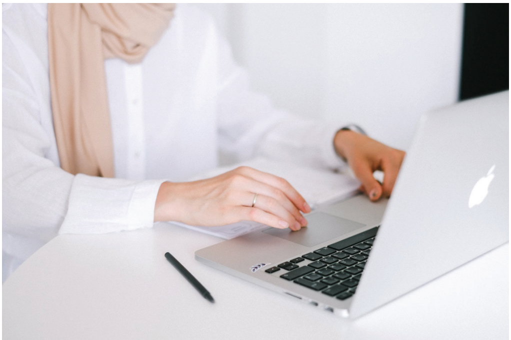

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Thanks so much.

Liz

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NOTES

2. Models of Motherhood Across Time

1 (Barker et al., 2014)
2 (Sousa, 2011)
3 (Altintas & Sullivan, 2017)
4 (Winnicott, 1960)

3. Psychological Models of Motherhood

1 (Dufresne, 2010)
2 (Verhoeff, 2013)
3 (Verhoeff, 2013)
4 (Palombo et al., 2009)
5 (Bowlby, 1958)
6 (Leiman, 1992)
7 (Watson, 1928)
8 (Baumrind, 1967)
9 (Elias et al., 2000)

4. Understanding the Diagnosis of Autism

1 (American Psychiatric Association, 2013)
2 (Hu-Lince et al., 2005)
3 (Zeldovich, 2018)

5. Behaviour Challenges We Face

1 (Jang et al., 2011)
2 (Dickerson Mayes et al., 2011)
3 (Hannon & Taylor, 2013)
4 (Lecavalier et al., 2006)
5 (Gorlin et al., 2016)
6 (Dickerson Mayes et al., 2013)
7 (Gorlin et al., 2016)
8 (Anderson et al., 2012)
9 (Gorlin et al., 2016; Rojahn et al., 2012)
10 (Duerden et al., 2012)
11 (Hannon & Taylor, 2013)
12 (Dickerson Mayes et al., 2011)
13 (Sreckovic et al., 2014)
14 (Coorg & Tournay, 2012)
15 (Mandell et al., 2005)

6. Risks to Mothers of Children with Autism

1 (Totsika et al., 2011)
2 (Zablotsky et al., 2013)
3 (Casey et al., 2012)
4 (Papageorgiou & Kalyva, 2010)
5 (Smalley, 2019)
6 (Fairthorne et al., 2014; Gorlin et al., 2016; Vasilopoulou & Nisbet, 2016)
7 (Estes et al., 2013)
8 (Estes et al., 2013)
9 (Fairthorne et al., 2014)
10 (Bromley et al., 2004; Obeid & Daou, 2015)
11 (Da Paz & Wallander, 2017)
12 (Bekhet et al., 2012)
13 (Smalley, 2019)

7. Mothers' Experiences of Trauma

1 (Yehuda et al., 1995)

2 (Seltzer et al., 2010)

3 (Bomyea et al., 2012)

4 (Duerden et al., 2012)

5 (Roberts et al., 2014; Schnabel et al., 2019; Stewart, McGillivray, et al., 2017)

8. What to Do About Trauma

1 (Costa et al., 2017)

9. Understanding the Impact of Trauma

1 (Yehuda et al., 2008)

12. How Is My Past Affecting Me?

1 (Siegal & Bryson, 2020)

2 (Bowlby et al., 1951; Schore & Schore, 2008)

3 (Tronick, 1989)

14. Develop Compassion For Yourself

1 (Neff et al., 2007)

2 (Chapman, 2009)