

*my*  
*unique*  
child

A Practical Guide to  
*Raising a Child with Autism*

J A S M I N E G O H



# endorsements

"I am glad to come across *My Unique Child*, which holds much practical wisdom. Such a guide for parents and caregivers of a child with autism in our local Asian context is a rare find. Containing real life stories, it is also a useful resource for educators and clinicians, to gain a deeper understanding of the experiences and issues faced by these families."

**–Dr Wei Ker-Chiah**

Senior Consultant and Head,

Adult Neurodevelopmental Service, Institute of Mental Health Singapore

[www.imh.com.sg](http://www.imh.com.sg)

"*My Unique Child* is a comprehensive guide for parents of children with autism. The topics are helpful for both the parents and the children, with practical and achievable strategies to work towards a full and balanced lifestyle for the whole family. Highly recommended for parents whose children are newly diagnosed."

**–Ms Cindy Kua**

Registered and Consultant Psychologist, Skillbuilders

[www.skillbuilders.sg](http://www.skillbuilders.sg)

"This is a work of the heart, for the heart of parents of a child with autism. It speaks of discovery, first of parents discovering themselves and then discovering the fullness of what their child can be in their unique selves, with their strengths and abilities which parents are in a unique position to uncover and develop. Jasmine has written an intensely helpful book, speaking with a directness and an empathy that says 'Help is here—you need it and you want it more than you realise.'"

**–Mr Lim Siong Guan**

Founding Chairman, Honour (Singapore)

[www.honour.sg](http://www.honour.sg)

*“My Unique Child* provides good advice to parents, caregivers, and anyone interested in autism. The Action Plan at the end of each chapter is particularly helpful.”

**–Mr Dennis Ang**

CEO, St. Andrew’s Autism Centre

[www.saac.org.sg](http://www.saac.org.sg)

*“My Unique Child* provides the hard facts that parents, who have just been told that their child has autism, need to know in an open and frank manner. Usually, one has to search the rigid terrain to dig deep for gems of truth and the way ahead. Here, Jasmine, a young Singaporean writer with a passion for people with autism, has put her career on hold to research, interview people, and pull the information together for your reading and action. This is a handy guide to map out options and possibilities for both your child and the family.

A worthwhile book for parents in Singapore, as they begin to explore the community from a different perspective after being told that their child has autism. You do not have to travel alone as you embrace and love your child with autism.”

**–Ms Carol Lim Seok Lin**

Special Education Consultant, The Butterfly Cove

[www.thebutterflycove.com](http://www.thebutterflycove.com)

“A volunteer with a heart for the autism community has come up with this practical guide on caring for an autistic child in the Singapore context. Each chapter ends with useful resources and authentic personal experiences. What I found most helpful is the idea of forming long-term goals—what, specifically, we should train our child in so that he or she can live comfortably after we are gone.”

**–Ms Brenda Tan**

Author of *Come into My World: 31 Stories of Autism in Singapore*

[www.come-into-my-world.com](http://www.come-into-my-world.com)

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*Acknowledgements*

*Resources*

*dedicated to shalomkids*

# *an opening note*

When I attended my first seminar on autism back in 2009, the lecturer showed us a video of a young woman named Carly, who had autism and communicated through spelling out words on a keyboard. That video warmed my heart, and I remember feeling very encouraged. In 2012, Carly and her father Arthur published a book titled *Carly's Voice*.

That video of Carly shaped my early approach towards autism, and I continue to be inspired by her life. Today, Carly has her own YouTube channel and an official talk show called *Speechless with Carly Fleischmann*.

Carly helped me to understand the world of autism a bit better. However, my experience on the ground opened my eyes to something even deeper. Through my time volunteering at special schools and in church, I interacted with many individuals who are affected by autism and realised one thing: The people who needed support, but weren't receiving much, are actually the parents and caregivers.

This book is written for families. The child has autism but the whole family is affected. Normal takes on a new meaning for each family member, whether young or old. The intent of this book is to support you and your family as you grow together at home and in the community.

There are many suggestions and strategies provided in the following chapters; however, not all of them will apply to your child at this point. Take what applies to your current situation and adapt it accordingly for your child. As time goes on and new situations arise, you can refer back to this book for more ideas.

*an opening note*

I understand that I'm an unlikely candidate to write this book. I'm not a health consultant, psychologist, or therapist. Neither am I a parent or sibling of a child with autism. As a writer by day, I have written this book simply as an advocate of people with autism (or autistic people, if this is the term you prefer).

Every child and every family is different. An idea that works for one may not work for another. Not all the methods suggested in this book will work for you, but I hope that the insights you gleaned from these pages will help you in adapting them into solutions for you and your family.

If you have any suggestions or questions, feel free to write to me. If you have a story to share, I'd love to hear from you. I may not have the answers or the right words to say, but I can share in your journey.

Cheering you on,

*Jasmine Goh*

jasmine@ouruniquestories.com

August 2017, Singapore





A dark grey background with several white puzzle pieces scattered around. One piece is in the top left, another is in the bottom left, and a few others are partially visible along the left edge. The text is centered on the right side of the page.

*Section I*

*first things first*



*“You never really understand a person until you consider things from his point of view, until you climb into his skin and walk around in it.”*

—Harper Lee, *To Kill a Mockingbird*



# coming to terms

**W**hether your child received the diagnosis of autism yesterday or five years ago, your experience and feelings as a parent are things that no one else will really understand. For some parents, these feelings never really go away, no matter how long it has been.

Wait, you may say, isn't this book about my child's autism? Why are we talking about my feelings?

While doing research for this book, I spoke with Ms Lim Seok Lin, an ex-principal of a special school and someone I respect for the work she has done and is doing. She said, "After diagnosis, the first thing you need to do is to understand how you feel because it shatters your dreams. Come to terms with it first. Deal with the grief first. Then you can go and help your child."

To put it bluntly, there is no point trying to sort your child out if you haven't got yourself sorted. Parents I spoke with shared about how they needed to grieve before they could do the best for their child.

We need to recognise that our emotional state is often a huge influence on our actions. Thus, identifying the feelings you have is the first step in your journey to raise your child.

## Let's Talk about Feelings

If your child has just been diagnosed as having autism, you may probably be feeling overwhelmed. Even if you have had your suspicions for a while and are relieved that you finally have a name and reason for your child's behaviour, it is still an emotional situation that can cause different people to respond in extremely different ways.

### Denial

Many parents struggle with denial at the start. Some go into a form of denial where they reject the diagnosis and refuse intervention therapy. Another form of denial is to believe that autism is an ailment that can be cured with the right treatment.

Some people take years to overcome it. You may initially find yourself in a state of denial, as it can be very difficult to come to terms with the fact that your child is not developing at the expected pace of a typical child.

To help yourself through the stage of denial, you can schedule a meeting with the healthcare professionals or attend a workshop on the subject of autism. Learning more about autism will help you to understand the need for an intervention programme.

### Guilt

Since no one knows what exactly causes autism, some parents start to blame themselves and question if it was something they did (or did not do) during the pregnancy or delivery that resulted in this developmental disorder. This may occur more frequently among mothers as they are the ones who bore the child.

Remember, you didn't cause autism to happen. It is likely that genetics plays a significant role but that is something you cannot control. Let me say it again, your child having autism is not your fault.

If you are experiencing self-blame, talk to someone you trust about these guilty feelings. Guilt is pervasive and damaging if left unchecked over time. Waiting too long to share guilt and fears can cause these feelings to grow out of proportion. Relief often comes when you express these feelings to someone.

## Anger

There can also be feelings of anger and bitterness. You may be angry with yourself, with your partner, with God, or even with parents who have seemingly healthy children.

It is best that you find someone to talk to. You could also seek out other people who are in situations like yours and listen to their experiences. Parent support groups are good places to start. Some groups meet regularly in a physical place, while others hold their discussions in an online forum.

## Shame

For some parents, feelings of shame and embarrassment are also experienced. In certain cultures, Asian in particular, a disability in the family is perceived to bring shame to the family and is often hushed up.

A similar but more subtle experience is feeling embarrassed. For example, some parents are embarrassed by the stares of passersby when the behaviour of their child attracts unwanted attention in public. In other cases, parents who hold powerful positions or have authority in the workplace experience feelings of incompetency when it comes to their child.

## Grief

Perhaps the most prevalent of all the emotions that you may go through, grief sometimes goes undetected because it does not present itself openly.

You may have had high hopes for your child and those dreams are now shattered. Not only that, you now have to make adjustments to your lifestyle and cope with challenges. In *Rainbow Dreams*, social worker Veronica Lim-Lowe from Rainbow Centre describes this grief like “the sudden loss of a loved one”.

Loss is very personal. Your partner’s grief may be very different from your own. Grief doesn’t mean you don’t or won’t love your child.

“Grief over the loss of the child you dreamed of does not invalidate any love you may have for the child,” says Laura E Marshak, author of *Married with Special-Needs Children: A Couples’ Guide to Keeping Connected* and a parent of a child with autism. “Parents may feel deep love for their child yet be overwhelmed with grief for the loss of life as they had known it or wanted it to be.”

For one parent, working through the grieving process proved to be an important step to acceptance of the diagnosis, and eventually modifying expectations. In her book *What I Wish I’d Known about Raising a Child with Autism*, Bobbi Sheahan writes, “Life for me became much easier once I realised that there was no amount

**Grief doesn’t  
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your child.**

of interaction, therapy, reading, prayer, support, or whatever that was going to change the fundamental chemistry of my beautiful child’s brain and central nervous system. This was a life-changing realisation.”

The time taken to come to terms with the fact that your child has autism differs from person to person. While parents eventually move into acceptance of their child's autism diagnosis, the journey continues to be full of ups and downs. It is natural to experience occasional bouts of disappointment, embarrassment, and resentment. You may even feel a deep sense of grief at various stages of your parenting journey, especially at development milestones and periods of your child's transition from childhood, adolescence, and to adulthood.

Veronica Lim-Lowe advises parents to “allow themselves time to grieve—to talk about it, cry over it, especially with their spouses, close family members or good friends, or even a counsellor if they need one. They need to be helped to recognise, understand, and prepare for grief that will come and go. This will make it easier for them to accept the grief each time it does occur. It is only when parents have sufficiently worked through their grief that they can move on.” (*Rainbow Dreams*, Tham-Toh Syn Yuen et al., p. 377)

**The time taken to come to terms with the fact that your child has autism differs from person to person.**

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*...the grief [parents] experience is like the sudden loss of a loved one, or like the unexpected death of a normal baby. It dashes any hopes and aspirations they may have of their child. The difference here is that the grief does not go away because the event is more permanent. There is also no clear transition out of the grief journey even after acceptance has been reached.”*

—Veronica Lim-Lowe

(*Rainbow Dreams*, Tham-Toh Syn Yuen et al., p. 375)

## Action Plan

- Go through each of the feelings mentioned—denial, guilt, anger, shame, and grief—and take some time to reflect on how you may have experienced each of these at different stages of your parenting journey.
- If you suspect that you may be suffering from depression, seek professional medical evaluation. Depression is a medical condition that requires treatment.
- Join a support group for parents. There is usually a parent support group in each school.
- Download the FREE 100 Day Kit for Newly Diagnosed Families of Young Children (0-5 years old). There is a separate one for school age children (5-13 years old). Created by Autism Speaks, it helps guide families through the first 100 days after the diagnosis. The online kit is available at [www.autismspeaks.org/family-services/tool-kits/100-day-kit](http://www.autismspeaks.org/family-services/tool-kits/100-day-kit).
- Set aside time each month for self-reflection of how the situation is affecting your emotional, spiritual, psychological, and physical health.

## Voices

*Hong Yu is currently in the technical path in a special school. His mother, Siew Yin, shares her thoughts on what she learnt was the best way to help her child.*



Whatever you do, you have to first accept your child and face up to it. Acceptance is most important. You may want to take him for different therapies and all kinds of treatment, but sometimes, when you go for many treatment methods, that may harm the child instead.

Someone once asked me, “Have you not ever hated your child?” My reply was, “I did when I couldn’t accept it.”

During that time, I was living in denial. All I could think about was autism and how to cure my son of it. At first, I wanted him to enter a mainstream school. After I realised that wasn’t possible, my next goal was to see him enter Pathlight School. However, the psychology assessment showed that he did not meet the requirements for Pathlight, so my next goal was to see him enter Eden School.

Around that time, I met another parent of a special needs child who told me, “Don’t lose sight of what is most important. Your child is your guide. Go to a school that is suitable for your child—not for you.”

I realised then that I had been blindly following the crowd.

Every child is different. Every child has different capabilities.

As with all children, children with autism can feel love. They may not express it, but they know it when you love them.

Now I tell myself, learn to accept criticism and think positively. Train him to live independently and appropriately as we may not accompany him for his whole life.

Help to promote public awareness for inclusion. Because children with autism are not able to communicate well, public awareness will help to reduce misunderstandings. Accept your child. Don’t be in a rush to cure him or her. Think about what your child needs, not what you want.

You may have reached the end of the book, but  
your journey doesn't stop here.

Hop over to

**o u r u n i q u e s t o r i e s . c o m**

for a complete collection

of the Voices you read in this book

and more.

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