

# Autism Decoded:

*The Essential Handbook*



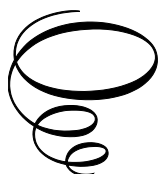
# Autism Decoded:

## *The Essential Handbook*

By

May Ng

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Autism Decoded: The Essential Handbook

By May Ng

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To my parents, your unwavering love and support have been the foundation upon which I have built my dreams. This book is a testament to the values you instilled in me, the lessons you taught, and the love that fuelled my aspirations. I am filled with love and gratitude always for being the champions of my happiness.

To my beloved children, Brendan, Darren and Corinne, you are my joy and light. As you navigate the chapters of your own lives, remember that you are the authors of your stories. With love as limitless as the spectrum itself, this book is dedicated to you.

To Eugene, to the remarkable journey we shared these past decades navigating the spectrum of autism, this dedication is a testament to the countless triumphs, the small victories, and the profound moments that made us stronger.



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## REVIEWS

*'Autism Decoded'* not only equips readers with the knowledge to comprehend the spectrum but also fosters a sense of empathy and appreciation for the diverse strengths within the autism community. This book is a guidepost, offering practical insights to enhance the lives of autistic individuals. It is an invaluable resource that empowers readers to embrace neurodiversity, fostering a world where understanding transcends preconceptions, and acceptance becomes the universal language.

—Dr Dominic Bray, Consultant Clinical Psychologist and parent of 2 autistic boys, United Kingdom

As a parent to a young autistic adult and an educator working with children on the spectrum, I find this book full of useful facts and guidance. It is like a go-to map to the world of autism and gives valuable insights of many things that will come your way from diagnosis. This book is concise and easy-to-read for anyone wanting to learn more about neurodiversity. What sets this book apart is Professor May Ng's empathetic tone. It feels like a conversation with a knowledgeable friend, making the journey of understanding autism much more relatable and comforting.

—Christine Green, mother of an autistic son and former UK National Autistic Society Early Bird Programme trainer and current educator, United Kingdom

This handbook stands out for its practical, bite-sized and comprehensive advice. Through *'Autism Decoded'*, Professor May Ng explores and explains a range of areas, from diagnosis, communications and puberty. She skilfully decodes the complex

topics through an autism lens, in order to bring invaluable information to the reader in an accessible way.

—Karen Massey, Autism Child Speech Therapist, United Kingdom

Professor May Ng breaks down complex concepts into simple, actionable steps, making it easy for readers to apply the strategies in real-life situations. It is a must-have book for any reader who simply wants to understand about autism, and for parents, carers and autistic people on how to navigate their personal journeys.

—Dr Jarod Wong, Consultant Paediatric Endocrinologist, Glasgow, United Kingdom

As parents of an autistic boy, we can relate so much to the wealth of information and advice given in this book '*Autism Decoded*'. Professor May Ng captures accurately the essence of autism and lays out the strategies and approach that is practical for any parent or caregiver to use. This book navigates the reader from early signs of autism to strategies for effective communication and many day to day challenges. It is your essential handbook that covers a wide range of topics. For parents navigating the challenges of raising an autistic child, this book is a lifeline. It provides a reassuring guide filled with practical tips, fostering a sense of empowerment and understanding of the diverse needs of individuals on the autistic spectrum.

—Arthur Leh and Petrina Yong, parents of an autistic son, Malaysia

Professor May Ng's book '*Autism Decoded- The Essential Handbook*' provides a wealth of information about autism without overwhelming the reader with technical jargon. It is a guide for parents, healthcare professionals, students, educators and anyone seeking clarity on various aspects of autism. Packed with ideas and peppered with encouragements, it is a great resource for everyone wishing to know more about the spectrum.

—Professor Ngee Lek, Consultant Paediatrician, Singapore

A handbook filled with wisdom by an author who writes with empathy and a wealth of experience as a devoted mother, dedicated paediatrician and a renowned researcher. This user friendly guide, navigates you through the day to day challenges of autism and provides great insight into autism itself, including diagnosis. This book should be a blueprint for all readers interested in this topic.

—Hannah Kyprios, Specialist dietitian, United Kingdom

Professor May Ng's use of inclusive language ensures that the book caters to a broad audience. The layout and organisation of the book make it exceptionally user-friendly. Readers can easily navigate through different sections, making it a handy reference handbook for various topics related to autism. Whether you are a seasoned professional or a newcomer to the world of autism, you will find the content accessible and relevant.

—Professor Wan Ariffin, Consultant Paediatrician, Malaysia

I wish I had this book when we were navigating our autism journey over 20 years ago with our son. Professor May Ng's book provides a clear and comprehensive guide not only to understanding autism spectrum and related conditions, but also the various strategies of addressing the challenges it presents, as well as the many resources available to caregivers. I find myself recognising and nodding along with all the methods that worked for us, that took years for us to discover by trial and error. *Autism Decoded* is an invaluable read and reference guide to parents, caregivers and those seeking a deeper understanding of the spectrum.

—Jennifer Summers, parent of an adult autistic son, United States of America.

Professor May Ng excels at providing clear definitions for terms related to autism. This clarity enhances the reader's understanding and ensures that key concepts are easily grasped. Above all, '*Autism Decoded- The Essential Handbook*' exudes positivity and

hope. It emphasises the strengths and potential of autistic individuals, promoting a mindset of acceptance and celebration of neurodiversity.

—Dr Udi Mahamithawa, Consultant Community Paediatrician and Autism Specialist, Lancashire, United Kingdom

Professor May Ng has managed to break down yet more barriers with her 4th book! As a nurse dealing with many patients on the autistic spectrum, this book is an excellent, simple, yet informative read about autism. This book will become an invaluable resource not only to myself and other practitioners, but also to patients and their families -it's a must-have book!

—Helen Day, Paediatric nurse, United Kingdom

*'Autism Decoded- The Essential Handbook'* by Prof. May Ng offers an insightful, compassionate, and practical guide for families navigating the complexities of autism. As a family, we found the book to be an invaluable resource, shedding light on the spectrum in a clear and accessible way. Prof. Ng's blend of professional expertise and personal experience provides comfort and understanding, helping us better support our loved ones with autism and neurodiversity. The practical strategies resonate deeply, making the book not only informative but also highly relatable. It empowered us with the knowledge to advocate more effectively and foster a nurturing environment for growth and development. We recommend it to anyone seeking to better understand and support individuals with autism and neurodiversity.

—The Parsons family, United Kingdom

Professor May Ng's first book *'A Journey with Brendan'* was an excellent introduction to autism and neurodiverse individuals based on her personal journey. This is a book in a totally different class. In *'Autism Decoded- The Essential Handbook'*, Prof Ng takes a real deep dive in to neurodiversity and autism, explaining to the

reader, the complexity of the topic in an exemplary way in a book of this size. The topic is vast, but she dissects them out to the reader in manageable chunks, and writes in plain English that all of us can understand. She explains the difficulties in the various topics, but repeatedly encourages us to see the positives and gives us hope to move forward. The 'Top tips' are absolutely brilliant, and so practical to a parent, carer or health professional often struggling against the odds. I am astounded by the amount Prof Ng has condensed in to this book covering not only complex medical issues but keeping it simple and practical at all times. I shall not only buy the book but distribute some copies to the parents of children who are neurodiverse, and I know that they will value it. I recommend this book without any hesitation to any parent or professional interested in knowing about neurodiversity.

—Dr Mohammad Didi, Consultant Paediatric Endocrinologist,  
United Kingdom

## FOREWORD

Professor May Ng, OBE is a consultant paediatric endocrinologist who is highly respected nationally and internationally. She was awarded Officer of the Most Excellent Order of the British Empire (OBE) in 2022 by Her Late Majesty Queen Elizabeth II for Services to People with Diabetes and People with Autism and Disabilities. She has been profiled in the Lancet journal in 2023. She continues to use her expertise to support children's health needs and has published extensively in this area. She also acts on the global stage, leading on key research, fundraising for autism and neurodiversity awareness, presenting at international conferences and often contributes to national and international policy.

In one of her previous books '*A Journey With Brendan*', she chronicled her lived, personal experience of raising her son who was diagnosed with autism at the age of three. She left no stone unturned in helping the reader to 'walk in her shoes', as she openly shared many of her personal life challenges, that other parents and carers in a similar situation could relate to and learn from.

Autism can be associated with challenges in social skills and communication, with no two diagnosed individuals being alike. Whilst there is no one specific way to support all those with autism, there are some guiding principles. In this book *Autism Decoded*, Professor Ng has built on her previous publication about her autistic son, by crafting an easy-to-follow reference book that breaks down the daunting area of the autism minefield, into concise, clear, manageable and easy-to-read chunks. Never cold and clinical, each chapter offers invaluable practical, concise

guidance on key areas within autism, from making the diagnosis through to everyday issues pertaining to childhood and early adulthood, seeking to empower and forge a ‘can-do’ mentality for the parents and carers of an autistic child. At the end of each chapter, the ‘Top tips’ distil the key chapter messages by offering related suggestions that the reader may find helpful for use in their real-life situations, be they a parent, a relative or a healthcare professional. I am sure that many parents and carers would benefit from having guidance such as is outlined here.

Professor Ng is extremely well placed to have written this book, given her lived experience of raising an autistic child and working in the field of paediatrics professionally, both of which add extra credibility to her suggestions for readers on how to approach the various elements of autism that she has addressed. Acknowledging that ‘one size does not fit all’, there are many realistic, applicable recommendations included, based on key themes that can affect autistic and neurodiverse individuals, such as toilet training, sleep management, behavioural strategies, and future employment considerations. The chapters on normal growth and puberty are also important and informative, reminding the reader to consider other concurrent medical issues that could be unrelated to autism and amenable to specific treatments where indicated. The chapter signposting the reader to other specific resources is also invaluable.

In practice, timely direct access to autism specialist teams and services can be challenging. The concise, accessible information presented here could serve as a very useful starting point for this, by providing a framework and offering references for further reading on particular topic areas. As a healthcare professional and a person, I always seek to treat others as I would wish myself and my family to be treated. The last chapter aimed at educators and healthcare professionals is something that should be read widely by this group, in the hope that it pushes them where needed to

adapt their communication methods, in respect to the autistic individual, to be less judgmental and more holistic.

I sincerely hope that this book will find its way into the hands of many parents, carers, educators and healthcare professionals who find themselves involved with autism and neurodiversity, be it for personal or professional reasons.

Dr Mayank Patel

Consultant Physician with family experience of autism



## INTRODUCTION

My first book *A Journey With Brendan* took more than 10 years to complete, detailing my journey as a paediatrician and mother navigating the intricate terrain of raising an autistic son. Autism, for many families, parents, caregivers, educators, and healthcare professionals, often presents itself as a perplexing enigma. Many of my students, friends, colleagues and families I have encountered over the years wanted to have access to a less medically jargoned, bite-sized source for understanding autism. I became convinced that this book was needed.

In this book, autism is described through the medical paradigm, and the book is not intended to alter the term 'autism'. However, it is important to recognise that the medical model has several limitations, such as its overemphasis on 'deficits' and 'disorders,' and a narrow focus on the individual. This model often fails to capture the broader perspective of autism. In contrast, the neurodiversity paradigm uses terminology like neurotypical, neurodivergent and favours identity-first language, referring to individuals as autistic rather than as persons with autism. This shift highlights that autism is an intrinsic aspect of a person's identity, inseparable from who they are.

For many families, parents, carers, adolescents and healthcare professionals, autism can be confusing and difficult to comprehend. While many books are written in a medically jargoned fashion, I hope that this book will make it easier to understand and give you, families, carers and healthcare professionals a chance to ask questions, share a discussion and

perhaps find an answer that you may be looking for. This book is not meant to be a detailed or an exhaustive review but is written for everyone who wishes to gain a practical understanding of autism in their lives.

I hope that this book will also be a valuable resource for caregivers, healthcare professionals, medical or nursing students to read and recommend to those who may wish to increase their understanding and to develop meaningful and supportive ways of communicating with autistic and neurodiverse individuals and their families. My aspiration for this book is to dismantle the barriers of complexity, offering a digestible and easily comprehensible source that not only de-mystifies autism but also fosters an environment for awareness, support, discussions and the potential discovery of answers sought by autistic individuals, families and caregivers. May it be a catalyst for fostering meaningful and supportive strategies, and nurturing a collective journey toward understanding, inclusion and empathy towards neurodiversity.

The chapters will shed light on the nuances of the autistic spectrum covering topics such as classification, assessments, behavioural and communication strategies, to more general topics like toilet training, food restriction issues and sleep training. In the subsequent chapters, I have described the important topics of understanding what is normal growth and puberty in childhood and implementing best practice standards in healthcare for autistic individuals. By conscientiously considering our choice of words, healthcare professionals have the potential to establish strong and enduring relationships with their patients. The concluding chapter contains numerous valuable links to resources which can be readily accessed that has been discussed in the relevant chapters.

In essence, this book aspires to be more than a mere informational repository. It is a narrative woven with threads of

empathy, knowledge, evidence-based research and a shared commitment to understand and unravel the mysteries of autism and neurodiversity.

Finally, be brave to venture and learn. I leave you with one of my favourite quotes and philosophy in life by Lucius Annaeus Seneca:

*“It is not because things are difficult that we dare not venture. It is because we dare not venture that they are difficult.”*

## AUTISTIC SPECTRUM CLASSIFICATIONS

Autistic Spectrum Condition (ASC) or Autistic Spectrum Disorder (ASD) is a common term used in the medical field as a complex neurodevelopmental condition that affects individuals in various ways, impacting their social interactions, communication skills, and behaviour. The term 'spectrum' signifies the wide range of symptoms, severity levels, and abilities that autistic individuals may exhibit.

The condition is not immediately obvious, but the indicators are usually present from early childhood, and these are characterised by a 'triad of impairments' which were defined in 1979 by the pioneers in the field of childhood development disorders, Lorna Wing and Judith Gould.

The triad consists of abnormal functioning in the following areas:

- Social communication
- Social interaction
- Social imagination and flexibility of thought

Sometimes signs can be seen in early infancy, while other children will appear to develop normally, and then suddenly become withdrawn or lose language and social communication skills they have acquired. Signs may often be noticeable by two to three years old.

Understanding the classifications and nuances of autism is often crucial for effective diagnosis, intervention, and support as we

delve into the various classifications and explore the diverse characteristics within this spectrum.

Firstly, it is essential to recognise that autistic spectrum conditions encompass several conditions formerly diagnosed separately, such as autistic disorder, Asperger's syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS). The merging of these diagnoses into a spectrum acknowledges the vast array of traits and challenges experienced by autistic individuals, but even diagnostic classifications can often be subjective.

At the core of the autistic spectrum are challenges in social interaction and communication. Individuals may struggle with maintaining eye contact, understanding social cues, or engaging in reciprocal conversations. Some may exhibit repetitive behaviours or intense but restricted interests, often focusing on specific topics with great detail and enthusiasm. Sensory sensitivities are also common, where certain sounds, smells, textures, or lights can be overwhelming.

Autistic spectrum conditions are typically classified based on the severity of symptoms, intellectual abilities, level of support required and additional challenges present. The International Classification of Diseases, eleventh edition (ICD-11) published by the World Health Organization similarly defines autism as a pervasive developmental disorder characterized by qualitative abnormalities in reciprocal social interactions and patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published by the American Psychiatric Association, outlines several diagnostic criteria. These criteria include deficits in social communication and interactions, alongside restrictive and repetitive patterns of behaviour, interests, or activities.

Within the spectrum, there are three main historical classifications based on the severity of symptoms described below.

### **Classic Autism**

This classification represents individuals with significant impairments in communication, social interaction, and behaviour. They may have delayed language development, struggle with basic social interactions, and display repetitive behaviours such as hand-flapping or rocking. Intellectual disabilities are common among autistic individuals, although some may exhibit exceptional abilities in specific areas.

### **Asperger's Syndrome**

Asperger's syndrome is characterised by milder symptoms when compared to classic autism, particularly concerning language and cognitive development. Individuals with Asperger's may have normal to above-average intelligence and often possess a strong grasp of factual information in their areas of interest. However, they may struggle with social skills and understanding non-verbal communication cues, leading to difficulties in forming friendships or navigating social situations.

### **Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)**

This classification is used when individuals display some symptoms of autism but do not meet the full criteria for Autism or Asperger's syndrome. PDD-NOS encompasses a broad range of symptoms and severities, making it a heterogeneous category within the spectrum. Individuals diagnosed with PDD-NOS may exhibit varying degrees of social and communication challenges, alongside repetitive behaviours or sensory sensitivities.

It is important to note that previous classifications of 'high functioning' or 'low functioning' autism can be subjective and do not fully capture the complexity of the autistic spectrum and its neurodiversity. Additionally, the DSM-5 now uses the term 'levels of autism' instead of 'functioning levels' to describe the support needs of autistic individuals. This is described below.

### **Levels of Autism**

This is classified into different levels of support based on the individual's level of functioning and the extent of support they require to navigate daily life effectively. These levels of support are outlined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5).

*Level 1* – This is currently the lowest classification with regards to support needs. Autistic individuals on level 1 will require some support to help with issues like inhibited social interaction and lack of organisation and planning skills. Individuals will find it hard to initiate and maintain conversations with others and many have difficulties forming relationships and friendships. They may feel a need to follow rigid behavioural patterns and are often very uncomfortable with change and new environments.

*Level 2* – Autistic individuals on level 2 often require substantial support and have problems that are more readily obvious to others. These issues may be significant difficulties with verbal communication, having very restricted interests, and exhibiting frequent, repetitive behaviours. Even with support, they may find it hard to communicate coherently and often face daily difficulties due to challenges in coping with change. They often speak in short sentences and only discuss topics of interest to themselves. They have poor eye contact and have significant difficulties in understanding or using non-verbal communications.

*Level 3* – Autistic individuals on level 3 requires the most support and are often unable to live independently. Signs associated with both Level 1 and Level 2 are still present but are far more severe and accompanied by other complications. Individuals at this level will have limited ability to communicate and interact socially with others. They have difficulties in both verbal and nonverbal communications and often avoid interaction with others. They show poor eye contact and limited interest in friends and have difficulties in forming friendships. They may face extreme difficulties in change to activities and routines, and develop repetitive behavioural patterns that may affect their ability to function. They often have high levels of distress and anxiety if a situation requires them to change focus or tasks.

It is important to note that while these classifications provide a framework for understanding, every autistic individual is unique, with their own strengths, challenges, and characteristics. Some may excel in academic or artistic pursuits, while others may require significant support with daily living skills. The diversity within the autistic spectrum underscores the importance of personalised approaches to intervention and support, tailored to each individual's specific needs and strengths.

In recent years, there has been growing recognition of the neurodiversity paradigm, which emphasises the value of neurological differences and challenges the notion of autism as solely a deficit to be treated or cured. Instead, it promotes acceptance, accommodation, and celebration of the unique perspectives and talents that autistic individuals bring to the world.

Autism is a complex and multifaceted condition that encompasses a wide range of symptoms and characteristics. Understanding the classifications within the spectrum of conditions, including autistic spectrum, Asperger's syndrome, PDD-NOS, and the levels of autism is useful for accurate diagnosis and accessing appropriate

support. Importantly, embracing the neurodiversity of experiences within the autistic spectrum fosters a more inclusive and supportive society that recognises and celebrates the strengths of all neurodiverse individuals, regardless of neurodevelopmental differences.

### **Top Tips**

- In understanding autism, gather as much information as you can, from others in the same situation, from experts, from books, from peer support and from the internet. Be wary that some information online may not be accurate.
- Remember that autism, neurodiversity and intellectual disability do not necessarily go hand-in-hand.
- Autism is a spectrum of conditions and an understanding that each child who are neurodiverse will have different abilities, strengths and learning challenges.
- Autism classifications should take into account holistic approaches as well as individual differences, strengths, challenges, and developmental history. Incorporating input from multiple sources such as parents, caregivers, educators, and clinicians can provide a more comprehensive understanding of the individual's functioning.
- Recognise the importance of considering contextual factors when classifying autism. Environmental influences, cultural norms, family dynamics, and socio-economic status can significantly impact how autism and neurodiversity manifests and is perceived. A classification system should be sensitive to these contextual factors to ensure accurate diagnosis and appropriate support but it can also be subjective.
- Understand that autistic individuals may present with different characteristics and needs at various stages of development. Classifications should not be static but rather

dynamic, considering the evolving nature of the spectrum and neurodiversity across the lifespan.

- Tracking developmental trajectories can help tailor interventions and support services to meet changing needs over time.
- Be mindful of the high prevalence of co-occurring conditions among autistic individuals, such as intellectual disabilities, Attention-deficit-hyperactivity disorder (ADHD), anxiety disorders, and sensory processing difficulties. Classifications should also account for these comorbidities and their impact on the individual's overall functioning and treatment approach. A comprehensive assessment should address both specific symptoms and associated conditions.
- Embrace a strengths-based perspective when classifying neurodiversity and the autism spectrum. Rather than focusing solely on deficits and challenges, recognise and leverage the individual's unique strengths, interests, and abilities. By identifying and nurturing strengths, classifications can be used to guide interventions that capitalise on the individual's assets, promoting positive outcomes and enhancing quality of life.
- By incorporating these tips into classifications, healthcare professionals can strive for more accurate, nuanced, and person-centred approaches that better support autistic individuals and their families.

## DIAGNOSTIC ASSESSMENTS

Determining the severity and levels of autism is a multifaceted process that involves assessments of various aspects of an individual's behaviour, communication skills, social interactions, and daily functioning. Since autism is a spectrum condition, it can manifest in a wide range of symptoms and severity levels, making it crucial to employ comprehensive evaluation methods.

In the United Kingdom, the National Institute for Health and Care Excellence (NICE) [[www.nice.org.uk/guidance/cg128](http://www.nice.org.uk/guidance/cg128)] provides guidelines for the assessment and diagnosis of autism, recommending a multidisciplinary approach involving input from healthcare professionals such as psychiatrists, psychologists, speech and language therapists, and paediatricians. Diagnostic evaluations typically involve a comprehensive assessment of the individual's developmental history, behaviour, communication skills, and social interaction, as well as standardised diagnostic tools and observation protocols.

The first step in determining the severity involves assessing whether the individual meets the diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as described in the previous chapter. This involves careful evaluation and assessments of deficits in social interactions and communications, as well as the presence of rigid, restrictive and repetitive behaviours or interests. Here, we will explore the various approaches and factors involved in diagnostic assessments of autism.

## **Observational Assessments**

Behavioural observations play a vital role in evaluating the severity of autism. Clinicians and trained professionals may observe the individual in different settings, such as at home, school, or during therapy sessions, to assess their social interactions, communication abilities, and behaviour patterns. These observations help to identify specific challenges and strengths exhibited by the individual.

### **Screening In Toddlers**

The Modified Checklist for Autism in Toddlers (M-CHAT) is a widely used screening tool designed to identify early signs of autism in toddlers aged 16 to 30 months. Developed by Robins et al. in 2001, the M-CHAT consists of 23 'yes' or 'no' questions, focusing on social communication skills and repetitive behaviours commonly associated with autism. It aims to detect possible indicators for further assessment. The M-CHAT has demonstrated good sensitivity and specificity in detecting autism risk in young children, making it a valuable tool for paediatricians and healthcare professionals in early identification and intervention efforts. However, it is important to note that the M-CHAT is a screening tool and not a diagnostic instrument. Positive screening results should be followed up with comprehensive diagnostic evaluation by qualified professionals to confirm or rule out autism. Moreover, the M-CHAT may have limitations, including false-positive or false-negative results, cultural and linguistic biases, and reliance on parent-reported information.

Therefore, it is essential to interpret M-CHAT results within the context of a child's developmental history, clinical observations, and additional assessment measures.