ASD Helping Hands

The Brain, The World and co-morbid conditions Information Booklet

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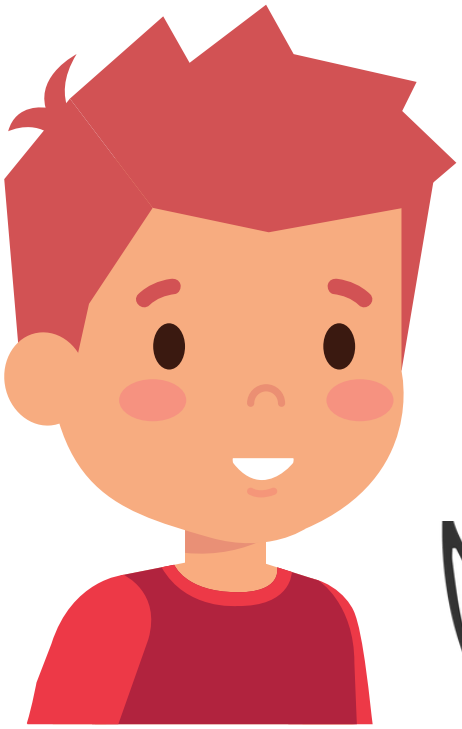
Meet Max



My name is Max. I am diagnosed with a ‘Syndrome Mix’

Let’s explore together what that means".?

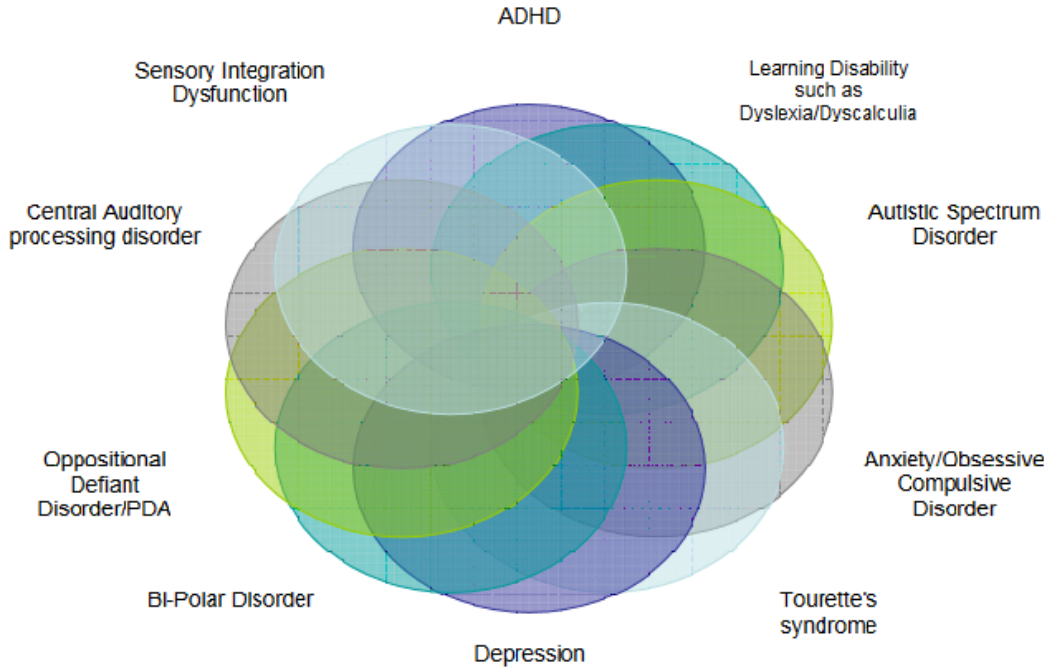
Being diagnosed with a ‘Syndrome Mix’ makes me different from those with Autism or ADHD. It means I have a mix of different problems

One possible combination is having a mix of ADHD, Tourette’s and Dyspraxia

The Basics

So it's called the 'Syndrome Mix' What does this mean? Certain conditions frequently cluster together in any combination.

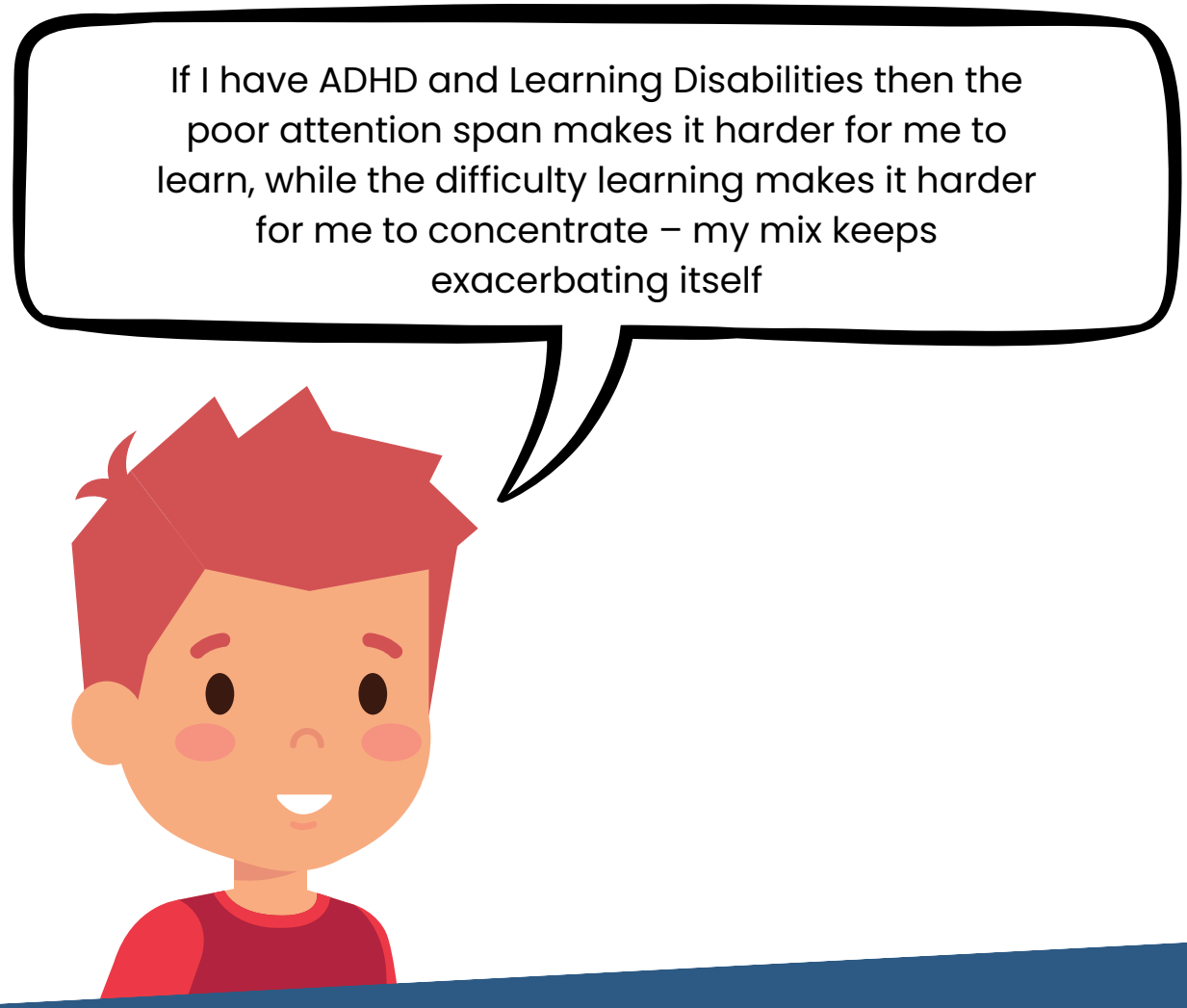
Think of it as one giant Venn diagram (see below)



If a child has any one of the problems out of the syndrome mix, there is a very significant chance of one or more of the other problems also occurring

Facts and Figures

- Two-thirds of children with ADHD have at least one of these other "co-morbidities" and one-third of children with ADHD have at least two of them.
- In a group of 100 people with ADHD at least 20-30 of these individuals will also have a diagnosis of ASD
- In a group of 100 people with a diagnosis of ASD 70% are likely to have a diagnosis of ADHD
- There are also one or two children or young people out of the 100 that ASD doesn't fit all their symptoms/behaviors
- The vast majority of children with Tourette's Syndrome also have co-occurring anxiety/OCD and ADHD



Gradient of Severity

Each area of difficulty in the 'syndrome mix' has a gradient of severity. In the 'syndrome mix' there will be conditions that have a greater impact on the quality of a child's life rather than others. These conditions need more pressing interventions and focus to be placed on. Other conditions may still need to be addressed but might not cause the same level of impairment. – These conditions can be referred to as 'shadow syndromes' (Dr John Ratey – psychiatrist). This makes it hard to diagnose because not only is there more than one condition they each have their own degree of intensity.

Where does Mixed Neurodevelopmental Disorder come from in terms of the 'syndrome mix?'

What we know is that many people have brains that function pretty well, although they might have their good and bad days. They process information in a typical way.

However, there's another group of people who experience things differently. They might have trouble sitting still, focusing, or find themselves fidgeting a lot. These individuals, particularly children and young people, might receive a diagnosis of ADHD. This diagnosis helps schools and colleges understand their needs and how to support them.

ADHD, along with conditions like ASD, Dyspraxia, and Dyslexia, have clear criteria for diagnosis. If someone meets those criteria, a pediatrician or psychiatrist can make a diagnosis.

But what about those who don't fit neatly into one category? What if they show traits of multiple conditions related to how their brains interact with the world?

For these individuals, it's not always helpful or accurate to slap on just one label. Instead, they might be diagnosed with Mixed Neurodevelopmental Disorder. These cases are more complex and involve a range of difficulties. Since these individuals are often quite young, it's not as simple as giving them a single diagnosis.

To understand Mixed Neurodevelopmental Disorder, we need to see how these different conditions overlap. This explains why it's sometimes more appropriate to use an umbrella term to describe the various traits they exhibit.

The conditions themselves according to the diagnosis manual DM-5

ADHD (Attention Deficit Hyper Active Disorder)

ADHD stands for Attention Deficit Hyperactivity Disorder.
According to the DSM-5 – ADHD is characterized by a pattern of behaviour, present in multiple settings (e.g., school and home), that can result in performance issues in social, educational, or work settings.

ADHD symptoms are divided into two categories:-

Inattention
And/or
Hyperactivity and impulsivity

Children must have at least six symptoms from either (or both) the inattention group of criteria and the hyperactivity and impulsivity criteria, while older adolescents and adults (over age 17 years) must present with five. Using DSM-5, several of the individual's ADHD symptoms must be present prior to age 12 years

While ADHD is often referred to people who havepoor concentration and attention spans, the opposite can in fact be true where a person can hyperfocus on a task to the detriment of other thing. It's more like difficulty regulating attention as opposed to poor attention.

ASD (Autism Spectrum Disorder)

ASD (Autism Spectrum Disorder) Is categorised in the DSM-5 with difficulties in the following areas:

Persistent difficulties in social communication and social interaction across multiple contexts i.e. home and school:

- Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions
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- Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

- Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following:-

- Repetitive motor movements, use of objects or speech, lining up toys, flipping objects, echolalia)

- Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour

- Highly restricted, fixated interests that are abnormal in intensity or focus

- Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment

Generalised Anxiety Disorder

Generalised Anxiety Disorder (GAD) is a common mental health condition characterised by excessive and persistent worry or anxiety about a wide range of everyday events or activities. People with GAD often find it challenging to control their worries, which can interfere with their daily functioning and quality of life.

Some key features of GAD include:

- Excessive Worry: Individuals with GAD experience heightened and persistent worry about various aspects of their lives, such as work, health, finances, family, or other personal issues. This worry is often disproportionate to the actual likelihood or impact of the feared event

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- Physical Symptoms: Alongside psychological symptoms, GAD can manifest with physical symptoms such as restlessness, muscle tension, fatigue, irritability, difficulty concentrating, and sleep disturbances. These symptoms can vary in intensity and may worsen during times of stress.

- Chronic Nature: GAD is typically a chronic condition, with symptoms lasting for months or even years if left untreated. The persistent nature of the disorder can lead to significant distress and impairment in various areas of life, including relationships, work, and social activities.

- Impact on Daily Life: GAD can significantly interfere with daily functioning, affecting work or school performance, relationships, and overall well-being. Individuals may avoid certain situations or activities to alleviate their anxiety, which can further restrict their life experiences.

- Comorbidity: GAD often coexists with other mental health disorders, such as depression, other anxiety disorders, or substance misuse disorders. Addressing these comorbid conditions is essential for comprehensive treatment.

Seperation Anxiety

Involves anxiety about being or becoming separated from home or attachment figures such as parents including fear that something might happen to either party causing the child or young person to be alone. Separation anxiety is often an early marker for other future anxiety disorders

Social Anxiety Disorder

Social Anxiety is when the anxiety/fear is centred on social situations where the child or young person feels subject to scrutiny/evaluation by others. The child or young person fears they will be negatively evaluated. In children, this anxiety must extend to relations with peers
not just with adults. This impairing reaction leads to avoidance or the experience of intense fear or anxiety. Only a small fraction of people who identify themselves as shy actually meet the criteria for social anxiety disorder

Selective Mutism

Is when a child or young person is perfectly capable of speaking when in a comfortable setting but consistently fails to talk in certain other social settings such as school

Panic Disorder

Panic Disorders are marked by repeated unexpected panic attacks accompanied by significant worry about their recurrence and fears of losing control or being ill or accompanied by maladaptive avoidance behaviours. There may additionally be expected (predictable) panic attacks. Panic expected or unexpected can occur as part of many psychiatric disorders such as any of anxiety disorders depression, bipolar etc. The presence of panic attacks usually belies a more severe degree of such underlying psychiatric disorders. Their presence can be noted diagnostically as a ‘specifier’ tag added to the primary diagnosis for example separation anxiety and panic attacks

Agoraphobia

This denotes fear/anxiety in at least two of the following environments: being in an enclosed space; being in open spaces; being in crowds; being alone outside of the house; or using public transport. There is an accompanying fear of inability to escape such places should panic set it

Unspecified Anxiety Disorder

This means an anxiety that causes functional impairment but does not fully meet criteria for any of the anxiety conditions above

Obsessive-compulsive Disorder

OCD is rooted in anxiety and apprehension.
Obsessions are repetitive thoughts or urges that are experienced by the person as unwelcome and basically senseless. The person feels compelled to try to ignore or neutralise the anxiety caused by these useless thoughts. Compulsions are the behaviours or mental acts that a person feels obliged to carry out in order to ward off anxiety caused by the obsessions. These behaviours such as counting, touching, rechecking or repeating words silently may need to be carried out according to rigid rules.

Typical OCD presentations include:

- Cleaning – including fear of contamination
- Counting or symmetry
- Harm (to self or others, perhaps with the need for repeated checking to prevent that harm)
- Taboo thoughts (including religious, aggressive, or sexually unwanted thoughts)

Sensory integration Dysfunction and Sensory Processing Dysfunction

The brain is a problem-solving machine like a computer. The difficulties (problems) come in the form of sensory input. Our computer (brain) collects that information from our sensory receptors, integrate it all, evaluates its importance, forms a plan and executes a solution

Sensory integration is defined as the process by which our brain interprets information that we gather from our senses and then outputs a meaningful response. Sensory Integration Dysfunction and Sensory Processing Dysfunction is the brain's inability to process sense correctly or adaptively. Dysfunction occurs when one or more of the links in the sensory network are in disequilibrium

- Intake by the sensory system. The brain takes in too much (called hypersensitivity) or too little (called hyposensitivity) sensory information
    - Hypersensitive individuals will avoid stimuli that excessively arouse them
    - Hypersensitive individuals will either ignore the stimuli or crave stimuli in order to arouse themselves

In either case, information is not received at the correct volume level

- Organisation by the nervous system. Sensory data is either not received, received inconsistently or disconnected from the correct sensory messages
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- Output of movement, speech, or emotion. Output problems can reflect a muscle control problem; or maybe the result of faulty input or processing i.e. garbage in, garbage out

Tourettes' Syndrome

Tourette syndrome (TS), often simply referred to as Tourette's, is a neurodevelopmental disorder characterised by repetitive, involuntary movements and vocalisations called tics. These tics can range from mild to severe and can significantly impact daily functioning and quality of life for those affected. Tourette's typically emerges in childhood, with symptoms often appearing between the ages of 2 and 12, peaking in severity during the early teenage years, and then often improving in late adolescence and adulthood.

Some key features of Tourette syndrome include:

Motor Tics: These are sudden, repetitive movements that occur involuntarily. Motor tics can manifest as eye blinking, facial grimacing, head jerking, shoulder shrugging, or more complex movements such as jumping or touching objects.

Vocal Tics: These are involuntary sounds or vocalisations. They can range from simple sounds like grunting, throat clearing, or sniffing to more complex vocalisations such as words or phrases. Coprolalia, which involves involuntary swearing or inappropriate language, is one of the more widely recognised vocal tics associated with Tourette's, but it only affects a minority of individuals with the disorder.

Premonitory Sensations: Many individuals with Tourette's report experiencing uncomfortable sensations or urges just before the onset of tics. These sensations can be relieved temporarily by performing the tic but tend to return.

Variability: Tics can vary in frequency, intensity, and type over time. They may also be influenced by factors such as stress, fatigue, excitement, and illness.

General Strategies for children and young people with a syndrome mix

Accepting your child or young person

Children who feel accepted, celebrated and secure in their relationships are free to explore, thrive and even be more cooperative

Brooks and Goldstein write in Raising Resilient Children (2001 p. 12) "accepting children for who they are an appreciating their different temperaments does not mean that we excuse inappropriate unacceptable behaviour but rather that we understand the behaviour and help to change it in a manner that does not erode a child's self-esteemand sense of dignity

Remember: "The thing I like about you best....is that you like me."

The concept here is that children and young people in the 'syndrome mix' often feel like they are being hit from all angles even from inside their own brains. They need you to reassure them that no matter what you're still there to support them and help them overcome their obstacles. Reassurance and love is the greatest tool against difficult and challenging behaviours. Telling children and young people with multiple traits that it is ok is often the simplest phrase but gets the biggest reward. You have to remember that your son or daughter might not be juggling just the ASD traits but also all the other traits of their own 'syndrome mix'.

Try not to take offence when presented with difficult behaviours

The child or young person suffers as well when misbehaving. They are the ones who are constantly thinking 'Why can't I be like all the other children', 'Why do I always misbehave'. The children and young people in the 'syndrome mix' will often or not actually 'shoot themselves in the foot' just as often as they bother others. Most of the time there problems are not fully within their control.

A**dopt a 'disability outlook'**
Your child or young person is a unique combination of various syndromes, making their mix distinct from others. As their caregiver, you play multiple roles, acting as their therapist, caregiver, punching bag, and safety net. They may often direct their frustrations and anger towards you, stemming from their neurobehavioral disabilities rather than physical ones. Despite your efforts to assist, they may resist, yell, and exhibit unwanted behaviors. It's crucial to understand that their actions are not driven by personality or will, but rather by the neurochemicals and neurotransmitters in their brain.

Children and young people with this mix of syndromes may struggle to ask for help or even recognize your attempts to assist them. Therefore, offering explanations and reassurance is essential. Their behaviors are often beyond their control, arising as uncontrollable outcomes of the various situations they encounter.

Minimise frustrations by taking a realistic look at the child you get every day
The reason behind this is that when your child or young person has a mixture of syndromes it is important that we are dealing with the right one. For instance one day the situations and day-to-day life might be looking as if your child or young person is presenting with autistic traits, the next day this might be drastically different and these traits are actually ADHD.

Forgive yourself, if you get it wrong
You are only human and will get it wrong more times than you get it right. Again I speak from experience that even with a high level of training and years working with autistic young people when it comes to my partner I still say the wrong thing, and act without thinking about his diagnosis. Each night, review how you've done that day and how you could do better. Make a note of strategies that have worked and strategies that haven't.

Manging behaviour in children and young people with a syndrome mix

Managing behaviour in children and young people in the 'syndrome mix'
Try and keep things positive. It is often hard to find positives when dealing with children with special needs. Ask yourself, what's going well? Before dealing with what's not working? One thing we always say as an organisation as you sometimes just have to laugh at some of the 'quirky' things those on the spectrum do. Try to laugh with them, not at them. Remember they may accomplish great things but it will be done at a snail's pace, life isn't a race to end so let your child or young person show you how to have an amazing journey.

Build upon a child or young person's strengths, harness their interests, and work with their likes rather than their dislikes. If they like Maths show them how maths can be found it many other subjects. If they like Minecraft tell them next time they need to write something in English to use their knowledge of that. If your child or young person is practically gifted don't try and force academic studies on them.

Positive behaviour reinforcement
This means that instead of punishing the negative behaviour you reward solely the positive behaviour. The reward must be immediate, frequent, powerful, clearly defined, clearly explained as to why they are being rewarded and consistent across all adults involved in the care of the child or young person (inclusive of schools).

Greene (1999) has a criterion for adopting reward systems
- The behaviour must be worth the effort of changing
- The child must have the ability to consistently control the behaviour
- The reward/consequence is likely to work
- Those with allegedly cooler heads can apply the plan consistently
- It is the child or young person's problem

With reward charts they need to not work so successfully when there is a financial element. You need to have an appropriate and sustainable 'carrot' to entice the child or young person with.

Avoid the four cardinal sins (Phelan 1994)

1. **Don’t nag – even simple comments about how was your day? May cause frustration**

2. **Don’t lecture – give one or two brief clear instructions**

3. **Don’t argue – ever tried arguing with someone that runs on logic I have. Guess what happens? You lose, every single time.**

4. **Don’t offer unscheduled spontaneous ‘advice’**

Consequences can be used to improve your child’s future decision-making

Give the child or young person the tools and explanation. Work on the underlying issues that create the behaviour. Make sure the consequence is realistic and useful. Keep consequences immediate and controlled. Do not attempt to talk about how the child might do things differently whilst they have only just misbehaved.

Using a no-fault approach
Avoid arguments based on whose fault it is. Just deal with the end results. It doesn’t matter why the child has misbehaved, they have and there has to be a consequence.

Try and then create a plan to prevent this from happening again, by explaining how the child or young person can avoid this situation in the future. This is particularly useful for those with ADHD.

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