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Autism Awareness in the times of COVID-19

COVID-19 has kept the world extremely busy to the extent that Autism awareness has taken a backseat. But let's remind ourselves that 2nd April is the World Autism awareness day and April the autism awareness month. These are challenging times for everyone and perhaps more so for families who have children with autism. To be able to help someone who has autism, it is important to understand him/her first. We have developed this psycho-educational material to help both professionals and lay people to understand what might trigger off challenging behaviour in someone with Autism. This material doesn't go into the details of all core symptoms of Autism but that's not the aim here.

Autism is a spectrum disorder. The spectrum not only includes people with different severities of autism but also with a wide variety of symptoms. The variability can be so much that if you know one person with Autism, you only know one person with Autism! Do not assume that all people with autism are the same. Just like we differ in our abilities, people with Autism differ in their abilities. And just like we have similarities with other people, so do people with Autism have similarities with other people. Remember, Autism may just be just one aspect of their personality. We shouldn't neglect other aspects of their personality. We therefore shouldn't refer to them as Autistic but rather someone who has Autism.

Children with Autism struggle to emotionally connect with others and others too find it difficult to connect with them. However it doesn't mean that these children don't feel emotions at all. A lot of these children feel happy, excited, sad, angry, afraid, surprised like most of us. However they struggle to express their emotions in ways that we understand. Apart from expecting and teaching them to express emotions more effectively, we also need to learn to be able to understand their emotions better. One of the most difficult things for a parent with a child with Autism is to be able to cope with their anger outbursts. Even though these outbursts seem completely out of the blue, there is often a trigger, which is easily missed. So with this background, let's try and understand what these triggers might be by looking into some of the important characteristics of Autism.

1. Communication difficulties - Imagine you have a tough day at work and are scolded by your Boss. What if the Boss is like a dictator and you can't say a word in front of him. Wouldn't it make you frustrated? And you are quite likely to express that frustration and anger at other people like your spouse and kids even when it's not their fault. Now if not being able to communicate in a particular situation can make you angry, then imagine children with Autism who struggle to communicate their needs, likes, dislikes, disapprovals etc on a daily basis! Wouldn't it make them more likely to act out in anger? There are times when these children are not even able to communicate that they are in physical pain. These outbursts actually help others notice them and fulfill their needs. It therefore becomes a functional behaviour for them.

2. Social difficulties - Think of a child you know who is shy & gets very anxious in public. If he is put in a situation where he is surrounded by people who expect him to behave 'normally' and bully him if he doesn't, don't you think he would be embarrassed, irritated and angry! Now, who defines what's 'normal' for this child! Most of the times, it is people who either don't know him at all or those that don't understand his difficulties in social situations. Children with Autism experience this all the time. They struggle to make eye contact or look at the other person's face while responding. Yet they are forced to. And they get bullied all the time by peers, family and even their own

parents who think that their child is acting up!

3. Changes in daily routine - Imagine you are told one morning that you have been transferred or you have lost your job. It would make you very anxious. We all like predictability to an extent. Children with Autism have a much greater need for sameness and predictability. They may have daily routines, which could seem impossible for them to change. Any unplanned events or changes to their daily routine can therefore trigger a tantrum. Even simple things like going to school via a different route can be enough to spark off a tantrum.

4. Repetitive behaviours - Think of a time when you are anxious. How do you cope with the anxiety? Some of you might bite your nails, or pace up and down or fidget with your fingers repetitively. We don't realize it but familiar repetitive actions help us calm down when we are anxious or uncertain of something. Children with Autism similarly engage in behaviours to cope with anxiety and uncertainty but these are so frequent, repetitive and stereotyped that they can appear odd. Some of these children also use these stereotyped, repetitive behaviours to self stimulate. However, parents and sometimes professionals often try and stop them from doing this because these seem odd to them! Obviously, it will trigger a tantrum.

5. Sensory issues - You are probably reading this post on your smart phone sitting in a room. The room is adequately lit. There is probably a little bit of noise from the AC, fan, and other activities at home. You can feel the circulating air on your skin or if it's still and hot you've probably rolled up your sleeves without being too bothered. There might be some irritating smell. The tea you're drinking doesn't taste the way you like but you're still grateful for morning cup! Now imagine that another person in exactly the same situation gets too distressed. The light seems too bright as if a torch is being shone in his eyes. The noise from the AC and fan seems as loud and irritating as if coming out of a loudspeaker in a marriage procession. The air on the skin seems irritating. The touch of the shirt on the skin in hot weather hurts too; it's probably not the right fabric. The smell is as if you're sitting inside a dirty public toilet. And that tea tastes like shit! Strange! But children with Autism have a lot of these issues that are not obvious to

most. A few of us may have an occasional and mild sensory hypersensitivity but imagine having a lot of these and to an extreme degree. Not surprising that these children with Autism can appear very distressed in public places without any reason that is apparent to us. Through the examples above, we have tried to make sense of the various reasons why a child with Autism may be upset, irritable, angry and sad most of the times. There may be many other reasons that are not listed above. The aim here is not to make the list all inclusive but to learn to always keep your “detective hat” on when looking after children with autism. Because, it is only when you can find out the reasons behind a certain problem that you can make any reasonable attempt to solve it. And this applies to perhaps everything in life!

A case vignette

Let’s try and put the above learning to test and try to explain what a child with Autism might experience in these current times when the COVID-19 pandemic has put the whole world under an unimaginable stress. And despite this virus having hijacked the world for some months now, we still can’t see a way through.

Imagine a 7 year old boy Amit (imaginary name) who has autism and has limited speech (single words). He struggles to express anything more than his basic needs like hunger, toileting, pain etc. Assume all the symptoms described above apply to him. How do you think he might be coping? His routine has changed completely. He is no longer attending his pre-school or therapy sessions. Daily visits to the park where he loved to run around and burn his extra energy have stopped. His Dad is not going to work because of the lockdown. Everyone at home appears tense and irritable. His Mum is constantly busy with the household work as all house help has stopped. This means she has little time for him. His rocking and arm flapping movements have increased which further irritates his parents. He hasn’t seen his favourite house-maid for 3 weeks. Amit has always struggled to cope with very small changes in his routine. But this is his whole world turned upside down and perhaps more when out of the blue, one day he watches everyone at home banging the utensils so hard that he had to keep his ears covered for an hour after the banging stopped! He remained extremely upset and aggressive the whole of next day.

If we try to logically understand Amit's behaviour, perhaps everything will start to make sense. The unimaginable changes to his daily life routine, no meaningful activities the whole day, hypersensitivity to sounds, difficulty in understanding this sudden change and inability to communicate his distress have made the situation worse for Amit. And at a time when he needs his parents on his side, they are irritable, stressed and have little time or patience for him. Watch this space for **strategies** on how to help Amit.

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