Autism from the Inside, Autism from the Outside



An Introduction to Asperger's Syndrome / ASD Level 1

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Introduction:





Discovering you have Asperger's / ASD can be a shock. However once you have a name for the condition, it can be easier for you & (hopefully) those around you to understand some of the experiences you have been dealing with.



It may take some time to learn about what it means to have Asperger's / ASD, & how it affects you. It can be unsettling at first to realise you are not quite who you thought you were.



You may have a different perception of life, or have difficulty comprehending things that are obvious to others.





You may have social difficulties, repetitive behaviour, intense interests, & a need for structure & consistency. However these can manifest in different ways for different people.

Since Asperger's / ASD presents very differently between individuals & and in various situations, it can be hard for those around you to recognise, understand & respond to it appropriately,

Although some people think it is a mental health condition or learning disability,
Asperger's / ASD is neither.

It can however occur alongside either or with other conditions such as dyspraxia or dyslexia.

Impacts of living with the condition:

Living with autism can make it difficult to understand the social conventions & expectations that other people take for granted, & even what people say.



It can be hard to understand non-verbal (unspoken) communication, verbal instructions & figures of speech that should not be taken literally such as "pull your socks up".



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It may be difficult for you to maintain eye contact or you may stare, either of which can unsettle people.



The combined effect of these challenges has been compared to finding yourself lost in a foreign country where you do not understand the language; not comprehending many things that other people automatically seem to understand, & therefore misunderstanding & making mistakes.



Other people may assume you are shy, anti-social, or even rude. They may struggle to gauge your abilities since you may find basic tasks difficult, whilst being intelligent & having exceptional skills in other areas.



Early years:



Many school students (especially girls), show few signs of autism in their early years.



These students can be quiet, solitary, model pupils, & mimic other pupils to fit in socially, but deteriorate academically & behaviourally on reaching secondary school.



Others may show a more marked difference from early on with unusual posture or gait, & how they interact socially; making friends, being in a group, fitting in, & regulating eye contact. This may lead to earlier recognition of the condition, & hopefully suitable support.



Unfortunately, one result of not being "part of the crowd" can be bullving.



Stimming:

A lot of autistic people stim.



This may be a movement; spinning, floating, rocking, bouncing, flapping hands, playing with fiddle toys, or a fascination with visual stimuli such as colour-changing lights or fireworks.



Stimming can be soothing or stimulating, bring joy or relaxation, & even be therapeutic in times of crisis.



Intense Interests & Repetitive Actions:

One thing you may notice is that you have intense interests which you can focus on for long periods of time. Another is that you may have some sort of repetitive movement.





In the past it was suggested that the repetitive movements of some autistic people should be discouraged as unhealthy activities. The same was also said of obsessive interests.



However, it is now considered that these activities, stimming (flapping hands, spinning, rocking, etc), or an obsession with a favourite subject should not be discouraged unless they are causing problems (danger to the person or those around them).





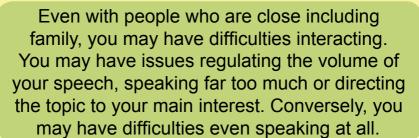
These activities can in fact be a way of coping with stress, or an intensely enjoyable, energising, & therapeutic activity.



Social Difficulties:









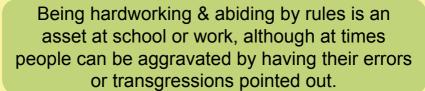


You might struggle to follow verbal instructions or understand the way people express phrases with implicit meaning (for example, someone suggesting you "put the kettle on" includes the expectation that you will make a hot drink & bring it to them!).



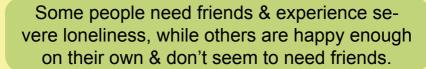
You may have general difficulties in fitting in, having an unusual dress sense, unusual eye contact, or being frustratingly literal & pedantic.













It is worth searching out groups for autistic people to see if this is a better way of getting to know people, however not everyone will become a friend just because they are also autistic!

Fluctuating Abilities:

A lot of autistic people appear very able in certain areas, particularly in favourite subjects such as computing, music, or an affinity with animals.





This makes it difficult for other people to understand that more basic abilities can be lacking, or even fluctuate daily.



Many everyday activities that most people take for granted such as getting somewhere on time, taking a bus, posting a letter, or making a cup of tea may prove almost impossible for people with Asperger's / ASD





Some autistic people create complex coping strategies for everyday things which can help reduce difficulties and anxiety.



Many people require support of some type, although it may be quite minimal. It can vary from minor things such as a chat once a week, help with filling forms or booking doctor appointments, to someone being around all the time, like a parent or support worker.







Others may find they can live a quiet life alone, coping with most things as long as they don't over-socialise.

Structure & consistency:





Often autistic people can be accused of being controlling as they try and deal with the world around them with complex coping mechanisms & structures to their lives.





It may mean taking a particular route to travel, a need to carry certain things everywhere, always having meals at certain times, even eating certain things on certain days.



Although reasons may seem incomprehensible at times to other people, reducing the uncertainty can alleviate some of the anxiety of life.

Masking:



Many people are able to "mask" their difficulties to pass as non-autistic, but this can be an exhausting way to live.



Ultimately, living this way without suitable support can lead to depression, anxiety, eating disorders, very low self-esteem & diminished confidence (particularly in autistic women, whose condition often goes unrecognised & unsupported for longer).



There may be difficulties with executive function (the ability to organise oneself, being in the right place at the right time, & bringing the right items). To some extent, coping strategies can help with this.

Sensitivities:

In an autistic person the senses can often be greatly heightened or reduced, causing pleasure or pain, and are sometimes used to soothe or purely for enjoyment (stimming). People may seek out extremes of one sensory experience, & try to minimise others.





Some people seek out sensations like coloured lights, specific colours, music or sounds, fabric textures, hugs, weighted blankets, strong flavours or food textures.





By contrast, other people are adversely affected by the same sensations, or may be totally oblivious to the joys of coloured lights or certain sounds.



Some people may enjoy movements such as spinning. Others may be in agony because of a sound no one else can even hear, or react badly to certain scents.

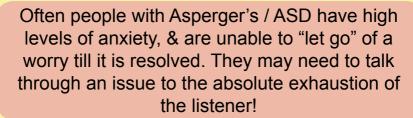




Anxiety, Overwhelm, Meltdown & Shutdown:

















Being overwhelmed by a variety of sensory stimuli (noise, stress, people, or even conflicting information) can cause shutdown (lack of speech or even ability to move) or meltdown (which might seem like a temper tantrum). It is helpful to learn what can lead to this, & what can help.

In the early stages it may be possible to avert either shutdown or meltdown by understanding and averting what is known to trigger it, & being aware of what can help recovery.

A crowd of people all trying to help & even touch are really not the answer!

What help might you need?

Despite initial appearances to the contrary, you may need support at home, work, or education.



This might include support at a social event or with travelling or shopping, discussing the situation and planning, making phone calls, or even ensuring you eat & drink regularly.



Initially you may still be learning about what will help you.



Sometimes the smallest thing will make a big difference (e.g. posting a letter which otherwise would never get to the post box).



Alone time might be vital for you, & at times interacting with people may be too much.



Many people find ways of coping with difficult, overwhelming situations, learning where they can go for some quiet, & carrying aids to concentration or coping such as stim toys, ear defenders, & music.



Your coping strategies may include always doing things the same way, or needing to have a timetable

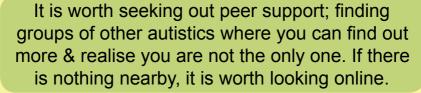


Those around you may need to understand that "it will be fun" or "it is easy" may not be the case, though giving practical help through a difficult situation can make it manageable.



What now?







Meeting or reading about other people with Asperger's / ASD may give you some ideas of what might help, & even just highlight what difficulties you may have.



You may be wondering who to tell, whether you will be accepted or even believed. Some people still think that autism only manifests like it does in Rain Man, so it is not something to be rushed.



Try talking to the people around you. If they are receptive, they may be able to help with something that will make a great difference to you.



There are many books available now, often with personal experiences, which you may relate to. Jessica Kingsley Publishers has a large number of books that you wouldn't see in ordinary bookshops.



You might consider counselling, but do make sure it is autism friendly. You may actually find yourself seeming more autistic to start with as you get used to things & discover who you are. Be gentle with yourself; allow yourself time to adjust, & forgive yourself for the things you struggle with.

& finally:

Autistic people vary tremendously. This guide is as comprehensive as possible, but is not exhaustive. You will find things mentioned that do not apply to you & probably things that have not been included.

This information was produced primarily focusing on the viewpoint of the less visible, more independent autistic who can often mask their difficulties, however much of it will also apply to people with more severe autism or learning disabilities.

"Finding out about my autism was, in some weird way, like being reborn, having the slate wiped clean. I had grown up being told & believing I was just naughty, a bad person, a freak, attention-seeking, a weirdo... feeling so broken and worthless."

"The diagnosis gave me an explanation for everything I struggle with, that it's not my fault."

"The clinician told me that I would now be able to "find my tribe" - & this is what I found in DAAS; the kindest place, where people are so accepting of any day that I'm struggling, & what wonderful friends I have made."

"We who have always struggled to fit in are all 'normal' together here. It is a safe space in a difficult world."

"DAAS made me feel very welcome & included."

- www.dorsetadultaspergerssupport.org.uk
- ☑ info@dorsetadultaspergerssupport.org.uk
- **f** Dorset Adult Aspergers Support Open Group
- Dorset Adult Aspergers Support (for meeting & drop in attendees)

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