



Part two : Autism

What is an Autism Spectrum Disorder (ASD)?

What is it?

An autism spectrum disorder (ASD) is a neurodevelopmental condition which affects the way a person communicates with, and relates to, other people and the world around them. The ways in which people are affected varies from one individual to another.

*“Once you’ve met one person with autism, you’ve met one person with autism.”
Dr Stephen Shore*

Always ask an individual for their preferred method of engagement and communication. It is estimated that 1 in 100 people in the UK are diagnosed with autism. This guide provides suggestions on how you could help . . .

Autism is . . .

- A neurodevelopmental condition
- A hidden disability
- A lifelong condition which affects people from all backgrounds
- A spectrum condition that effects each individual in different ways

Autism is not . . .

- A mental health condition nor learning disability
- Easily identifiable
- Shown in the same way in every autistic person, each person is individual
- A condition that you grow out of when you reach adulthood
- Always diagnosed in childhood

Autism is also known as :

- Autism Spectrum Disorder (ASD)
- Aspergers Syndrome
- High functioning
- Autism Spectrum Condition (ASC)
- Childhood Autism
- Pervasive Developmental Disorder (PDD-NOS)

NB: diagnosticians may use a range of descriptive terms such as classic autism, core autism, childhood autism etc, which can be confusing.



PDD – NOS	AUTISTIC DISORDER	ASPERGERS DISORDER
Impaired social interaction	Impaired social interaction	Impaired social interaction
OR	AND	AND
Impaired communication	Impaired communication	Impaired communication
OR	AND	AND
Restricted repetitive and stereo-typed patterns or behaviours, interest and activities	Restricted repetitive and stereo-typed patterns or behaviours, interest and activities	Restricted repetitive and stereo-typed patterns or behaviours, interest and activities

What are the signs and characteristics of Autism Spectrum Disorder?

Autism is often still regarded as an ‘invisible disability’.

Autistic people experience the world differently and can have difficulty instinctively understanding what other people are thinking and feeling.

Autism is a ‘spectrum disorder’, this means that it affects people in different ways across a range of abilities, strengths and difficulties.

This neuro-diversity affects a person’s ability to instinctively understand other people, and it varies according to whether or not a person is capable of spoken language, eye contact, or whether they speak a lot and like to be around other people.

Some autistic people “mask” or “camouflage” their autistic traits and thus autism presentation can differ for many reasons, including gender and cultural factors.

It is also common for autistic people to experience:

- issues with processing sensory information
- other conditions, such as ADHD, anxiety, depression or a learning disability
- repetitive behaviours
- a preoccupation with an intense/special interest

Autistic people are likely to be vulnerable to exploitation, and often experience stigma, abuse and hate crime. They may be more vulnerable to abusive relationships and may not have a good support network.

They can also experience difficulties throughout their lives in:

- education
- employment
- health
- housing
- intersectionality – autistic people may belong to other marginalised groups (i.e. high rates of LGBTQIA+) which can complicate their situation and increase potential vulnerability.

Other co-occurring conditions:

Autistic people may have additional distinct health conditions that are not directly a part of their autism, but which are shown to occur in higher numbers in the autistic population. Some common co-occurring conditions include, but are not limited to:

- Anxiety
- Attention Deficit Hyperactivity Disorder (ADHD)
- Dyspraxia
- Dyslexia
- Epilepsy
- Obsessive Compulsive Disorder (OCD)
- Oppositional Defiance Disorder (ODD) /DCD Developmental Co-ordination Disorder
- Gastrointestinal issues
- Sleep difficulties/disorders
- Eating Disorders
- Ehlers-Danlos

It is important to recognise that autistic people are not excluded from other mental health and physiological conditions and often experience these at higher rates than non-autistic people.

What this means in practice? How can I help?

Autistic people are affected in a variety of ways and to varying degrees, which is why autism is referred to as a spectrum. It is important to remember that the autism spectrum is broad, and therefore different autistic people may display either all, or only some, of the characteristics described in the following sections.

Communication (verbal and non verbal)

People usually use a variety of methods to communicate with others, from speech to body language. Autistic adults may have significant differences in the way their communication has developed. This varies from one individual to another, and some may have little to no verbal communication. Some autistic people can develop language very quickly and can be very articulate, but may experience a delay in processing through verbal communication.

An autistic person may:

- have a delay in processing
- have delayed development of speech or no speech
- often use words and phrases out of context
- not respond when spoken to
- be better at using language than understanding it or vice versa (where their expressive and receptive language can be very different)
- not understand or misunderstand figurative language
- not understand the to-ing and fro-ing of a conversation
- repeat words and phrases other people say
- not appreciate the need to communicate information
- find it difficult to pick up on tone of voice, the meaning of gestures or facial expressions
- not recognise that different language should be used for different relationships (e.g. friends, family, professionals, strangers).

"It's exhausting because it's like you're doing math all day"

Kevin Pelphrey, Yale Child Study Center



Top Tips for :

Supporting Communication

- Endeavour to **maintain one point of contact** in the organisation for the person.
- **Ask and note** the person's preferred method of communication.
- Establish if the individual prefers to be known as an autistic person or person with autism.
- Use a **clear, calm voice**.
- Ensure you **have the person's attention, say their name** before speaking to them.
- **Minimise sensory distractions** such as noise, bright lights and busy rooms.
- Ask specific questions and **keep things short and straightforward**.
- Explain things clearly, **avoid jargon**, always **check** you have been understood, and **follow up** after the meeting/conversation.
- **Avoid** using idioms, metaphors and similes.
- **Allow** the person some time to process information and check that they've understood (i.e. 15 seconds).
- **Use facts to explain** things, avoid analogies and **never use sarcasm**.
- **Don't rely** on body language, gestures and tone of voice.
- **Use pictures** to help explain things.
- **Do not overload** the person with lots of verbal information.
- Consider using **clear and simple written lists** of specific things that need to be done.
- **Allow time** to express their view and be patient. Increased anxiety may reduce the ability to communicate verbally.

Social Interaction

Autistic people may find it difficult to evaluate social situations, be around other people, understand the unwritten rules of behaviour, and create or maintain relationships. Together this might make it hard for someone on the spectrum to make and keep friends.

An autistic person may:

- sometimes appear aloof and indifferent to other people
- struggle with physical contact while others may seek it for sensory reasons
- passively accept social contact and show some signs of pleasure in this
- approach other people but in an inappropriate and/or repetitive way, paying little or no attention to the responses of those they approach
- try hard to be sociable though they may still find it difficult to understand non verbal communication, including facial expressions
- appear socially skilled but this ability may falter in times of change and/or stress

Often autistic people would like to make and keep friends though they may need help and support to achieve this.

Top Tips for :



Supporting Interaction

- If necessary, **provide appropriate support in social interactions** so that an autistic person can gain valuable social skills and independence.
- **Provide opportunities to engage** in a variety of activities using knowledge you may gain from the person's interests, skills and strength.
- **Provide opportunities to reflect** on social interaction with an autistic adult to ensure they develop their social understanding.
- **Speak clearly and avoid** irony, sarcasm, figurative language and implied instructions.
- Good practice would be to **obtain information** on the tenant, further information available in the Wales and West example.
- **Do not assume** that an autistic person will understand the concept of things they have not experienced i.e. being homeless or going to court (link with social imagination).



Social Imagination

Difficulty arises in social imagination due to inflexibility of thought and/or behaviour, a need for routines, and an inability to imagine what happens next. Autistic people may also have intense interests and fascinations around certain objects or subjects.

An autistic person may:

- become distressed if a familiar routine changes
- have difficulty in planning and organising
- struggle to follow lengthy instructions or directions if they are not written down
- find transitions difficult
- be reluctant to deviate from one way of doing things
- find it hard to work out what other people are likely to do and cannot make sense of why other people do what they do
- find it hard to understand what is expected of them and find it difficult to work out what information is important/relevant to give to you
- be unable to take someone else's perspective or point of view
- not always be able to realise that some things they say could offend others
- often pay particular attention to unusual details and struggle to see the bigger picture
- find it hard to imagine what other people are thinking and so can appear to be less socially skilled and come across as naïve and on occasions rude.

Intense Interests

Everyone has their favourite pastime or activity that they enjoy and tend to engage in frequently, but this interest does not interfere with their day to day life.

Some autistic people may enjoy a repetitive activity or show repetitive behaviours.

This might be something as simple as flicking the fingers, or an object or something more complex like following a certain routine travel route.

They may also have rituals, or have a repetition of a sequence of unusual bodily movements (possibly related to anxiety).

It is important that we recognise and respect how important intense interests are the lives of autistic people such as trains, movies, literature, gaming, autism, etc.

“Special interests save lives.”

Carly Jones MBE

“My favourite characters are like loved ones. They are always there for me, I can never disappoint them. They will never reject me or surprise me, and I can never say or do the wrong thing. When I’m lonely and exhausted and overwhelmed, they comfort me, asking for nothing in return.”

Emma Durman

Top Tips for :



Managing an individual’s intense interest

- **Be tolerant.**
- **Support the person** to use these as motivators or rewards when other activities are completed, but **never use withdrawal** of an intense interest as a punishment/consequence.
- **Do not make fun** of or criticise their interest.
- If the interest is interfering with learning or daily activities, **encourage engagement** in activity only at specific times.
- Look for ways to expand the special interest into a useful activity.
- **Use the special interest as a focus** when supporting the adult and to encourage more meaningful engagement. Remember that while you may not immediately recognise the value of an intense interest, it can be an important, even necessary part of the autistic person’s life.

Sensory Processing

Our bodies and the environment send our brain information through the senses. We process and organise this information so that we feel comfortable and secure. This helps us to understand the world and respond appropriately. Our sensory processing systems allow us to receive, register and pay attention to sensory information. We then process this information to make sense of it, prioritise it, and decide if a response is needed. This response may be an emotion, thought or behaviour.

Sensory processing differences for autistic people could include

- Over (Hyper) or Under (Hypo) sensitive
- Filtering sensory information
- Level of arousal
- Sensory defensiveness
- One sensory input at a time
- Attaching a meaning to a sensation
- Two or more senses being linked (synaesthesia)

These different sensory perceptions can sometimes cause pain, distress, anxiety, fear, or confusion and can result in behaviours that may appear challenging. Some examples are provided below:

Hypersensitive	Hyposensitive
Dislikes dark and bright lights	Moves fingers or objects in front of the eyes
Looks at minute particles, picks up smallest pieces of dust	Fascinated with reflections, brightly coloured objects
Covers ears	Makes loud rhythmic noises
Resists touch	Likes vibration
Avoids people	Spins or runs around in circles
Avoids smells	Smells self, people and objects
Moves away from people	Seeks strong odours
Places body in strange positions	Rocks back and forth
Difficulty walking on uneven surfaces	Bumps into objects and people
Turns whole body to look at something	Lack of awareness of body position in space

Taken from 'Sensory Issues in Autism' by the Autism and Practice Group, East Sussex County Council

For autistic people the brain tries to process everything at once without filtering out the less important things, for example: background noise, wallpaper, people moving about, and the feel of clothes on their skin. This results in sensory overload. When this happens, you may find the individual either having a 'meltdown', or even 'shut down', which is beyond an autistic person's control, as it is an involuntary response. The natural response to a threat is 'fight', 'flight' or 'freeze'. A 'meltdown'; is the body fighting the stimuli, a shutdown; is the body freezing in response, and flight; is the desire to get away from the situation.

'Meltdown'

"It literally feels like my head is imploding. Building up to it gets overwhelming, but an actual meltdown is just like... like your brain is ceasing to exist. Of course, it doesn't actually, but I lose control of my muscles and ability to talk, I can't modulate my voice or really send any signals from my brain to my body to calm down. It's as though my brain, as a last-minute thing, sends a bunch of energy to the rest of my body, but there's no instructions for how that energy should be used, so it just goes all over and is out of my control."

Shayna G

'Shut Down'

Some autistic people describe that they sometimes enter 'shut down' after a 'meltdown' – kind of during recovery mode. It is important to understand that the autistic person may be unable to communicate, move, or interact with you, or the environment. They may feel incredibly vulnerable in this state and hypersensitive to touch. You should reduce sensory input including keeping communication as brief and calm as possible.

"Shutdowns are hard for me, I become extremely hypersensitive to sensory input, to people in my environment, I even lose my verbal ability. It's hard for my loved ones too, because they want to comfort me, but any social demand, like speech, is unwelcome, and physical touch, like hugs or a tap on the arm can be excruciating. If an autistic person is consistently stressed and overwhelmed for a long period of time, they can enter an extended shutdown sometimes referred to as 'autistic burnout'. This can drastically reduce an Autistic person's ability to function for weeks, months or even years."

Emma D



Top Tips for :



Relating to sensory issues

- **Ask and observe** the person and **try to learn** which sensory issues they may have — the more you can learn **and understand**, the easier it will be to support them.
- **Be aware** that if they are upset, distressed or behaving in a challenging way, **consider** whether this is being caused by sensory issues. In this case, dim lights or reduce noise levels to see if there is improvement.
- Be aware that they may only be able to utilise one sense at a time, for example, not looking at you does not mean not listening to you.
- **Remember** that when you've identified issues which trigger sensory problems, try to **avoid these where possible** and **advise others** where appropriate.
- **Have a quiet time/ space** so that they can relax and regain their composure.
- Note that sometimes ear defenders, sunglasses and other sensory reducing equipment can help.
- If meltdown occurs, remember to **stay calm and speak softly** to the individual using direct short sentences and offer a quiet place to recover if required.
- If shut down occurs, remember to offer the Autistic person **a safe, sensory friendly environment to recover**, or ideally **make adjustments** to the current environment (i.e. turn off bright lights, close blinds, reduce noise etc).

Anxiety is one of the most debilitating issues experienced by an autistic person

Most individuals experience anxiety at one time or another. For some, this is a chronic issue that affects every aspect of their lives. For others, it may occur in relation to specific events or activities or it may come and go throughout a person's life.

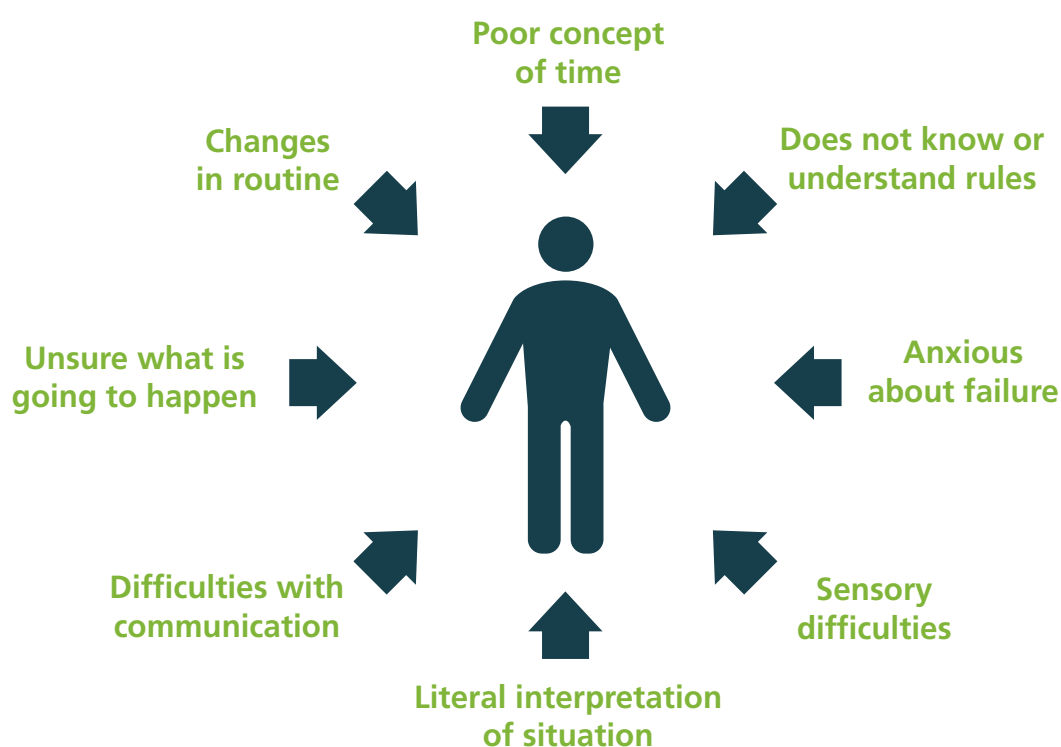
Anxiety is often the cause or trigger for other behaviours that impact the autistic person's daily life. They may engage in behaviours that are a way of communicating their anxiety or be caused by them avoiding anxiety provoking situations or people, or by eliminating anything that is not predictable.

Some of the behaviours you might see are

- increase in repetitive behaviours or involuntary movement
- restlessness and over activity
- becoming withdrawn and resisting any interaction with others
- avoidance
- limited attention span
- low mood
- becoming distressed
- self injurious behaviours
- using alcohol to cope with anxiety

Being aware that someone is anxious is the first step in trying to help. The causes of anxiety are numerous, some are obvious, and some are not, which makes it very difficult to eliminate them.

Here are just a few examples that may cause anxiety:





Top Tips for :

Supporting with anxiety

- **Adapt your communication** appropriately to meet the individual's preferences.
- **Provide structure** to the individual's appointment or visit.
- Consider changing the environment to **reduce sensory impact**.
- Give **clear, explicit** instructions/details of what you and they will do.
- Undertake things as planned, **be on time** for meetings and don't make last minute changes where possible.
- **Give advance notification/warning** before maintenance activities are about to start, or something is about to end.

Repetitive Behaviours / Self-regulatory Behaviours

The term repetitive behaviour is used to describe specific types of behaviours that are sometimes seen in autistic adults. These behaviours may appear odd or unusual to those who do not understand their function.

Some repetitive behaviour is sensory seeking and is sometimes referred to as self-stimulating behaviour, also known as 'stimming'. This behaviour may involve any or all of the senses in various degrees. Some repetitive behaviours are obvious while others are more subtle and hard to detect.

Tactile (touch)	scratching, clapping, feeling objects, playing with strings, hair twisting, toe-walking
Vestibular (movement)	rocking, spinning, jumping, pacing
Proprioceptive (body position)	teeth grinding, pacing, jumping, banging against hard objects
Visual (looking)	staring at lights, blinking, gazing at fingers, staring at the corners of ceiling
Auditory (hearing)	tapping fingers, snapping fingers, grunting, humming
Olfactory (smell)	smelling objects, sniffing people
Gustatory (taste)	licking objects, placing objects in mouth

Why repetitive behaviours?

Some of the possible reasons for using repetitive behaviour are outlined below:

- self-regulation, which helps the individual become calm and overcome situations of stress or upset
- demonstrating excitement
- providing the person with an escape route when they are overwhelmed or wound up
- enjoyment, some autistic people find the behaviour pleasurable even if causing injury to themselves
- a way of avoiding a task or activity

Some people learn to monitor their behaviours so they can engage in them in 'safe' environments (e.g. at home). It is important to understand that these repetitive behaviours are something that the person needs to do - do not force them to stop unless it becomes dangerous to themselves, or others.

Top Tips for :



Managing repetitive behaviours

- Try to **be tolerant**.
- If the behaviour is causing, or likely to cause, the person harm, ask to be referred to an Occupational Therapist who might be able to help reduce or change these behaviours.
- Any increase in these behaviours is often an indication of raised anxiety levels.
- For acute increases in this behaviour, **be a detective**. Try and **work out** what may be causing anxiety **and assist** with the cause.
- **Don't reprimand** the person for their behaviour — any attention is likely to increase the behaviour.
- **Read the other sections in this guide**. Implementing advice about managing anxiety and behaviours may reduce stimming behaviours.