# Autism What do you know?





### What is autism?

Autism is a lifelong developmental disability which affects how people communicate and interact with the world. More than one in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK.



### **Being autistic**

Autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses. In this session, we will explore some of the difficulties autistic people may share, including the two key difficulties required for a diagnosis.

#### Getting words right about autism

The language we use to talk about autism is important because it can affect what people think about autistic people. Getting it right will help people get the right kind of support and services.

#### Five top tips

1. Talk about autism positively. There are many positive things about being autistic. Many autistic people see autism as part of who they are, rather than something separate, and prefer to be described as 'autistic' or 'on the autism spectrum' – rather than as 'someone with autism'.

2. Do not use negative language like suffering from autism, symptoms and treat. Instead talk about characteristics, support and reasonable adjustments.

3. Every autistic person is different. Try to make sure people know this in all communications.

4. Autism is not a learning disability or a mental illness. But some autistic people also have a learning disability and many people have a mental health problem.

5. Some people on the autism spectrum understand language very literally. Avoid phrases that don't say what they mean. Like "it's raining cats and dogs". Use clear, everyday language.



https://youtu.be/Lk4qs8jGN4U

#### **Social communication**

Difficulties with interpreting both verbal and non-verbal language
 Some autistic people are unable to speak or have limited speech while other autistic people have very good language skills but struggle to understand sarcasm or tone of voice.

Other challenges include:

-taking things literally and not understanding abstract concepts -needing extra time to process information or answer questions -repeating what others say to them (this is called echolalia)

#### **Social interaction**

Autistic people often have difficulty 'reading' other people - recognising or understanding others' feelings and intentions - and expressing their own emotions. This can make it very hard to navigate the social world.



#### Getting and keeping their attention

•Always use their name at the beginning so that they know you are talking to them.
•Make sure they are paying attention before you ask a question or give an instruction. The signs that someone is paying attention will be different for different people.
•Use their hobbies and interests, or the activity they are currently doing, to engage them.

#### **Processing information**

An autistic person can find it difficult to filter out the less important information. If there is too much information, it can lead to 'overload', where no further information can be processed. To help:

•say less and say it slowly

•use specific key words, repeating and stressing them

don't use too many questions

•use less non-verbal communication (eg eye contact, facial expressions, gestures, body language)

•use visual supports (eg symbols, timetables, Social Stories) if appropriate

•be aware of the environment (noisy/crowded) that you are in. Sensory differences may be affecting how much someone can process.

#### Avoiding open-ended questions

•Keep questions short

- •Ask only the most necessary questions
- •Structure your questions, eg you could offer options or choices
- •Be specific. For example, ask "Did you enjoy your lunch?" and "Did you enjoy maths?" rather than "How was your day?".

#### Ways to ask for help

If appropriate, give autistic people a visual help card to use to ask for help.

#### **Being clear**

Avoid using irony, sarcasm, figurative language, rhetorical questions, idioms or exaggeration as autistic people can take these literally. If you do use these, explain what you have said and be clear about what you really mean to say.

#### **Distressed behaviour**

Use a <u>behaviour diary</u> to work out if the behaviour is a way of telling you something. Offer other ways of expressing 'no' or 'stop'.

#### Reactions to "no"

-Try using a different word or symbol.

-Autistic people may be confused about why you said no. If it's an activity that they can do later on that day or week, try showing this in a timetable.

-'No' is often used when someone is putting themselves or others in danger. If it's a safety issue, look at ways of explaining danger and safety.

-If you are saying 'no' because someone is behaving inappropriately, you may want to change your reaction to their behaviour. ---Try not to shout or give too much attention, a calm reaction may help to decrease this behaviour in time.

-Set clear boundaries and explain why and where it is acceptable and not acceptable to behave in certain ways.

#### **Repetitive and restrictive behaviour**

With its unwritten rules, the world can seem a very unpredictable and confusing place to autistic people. This is why they often prefer to have routines so that they know what is going to happen.

Autistic people may also repeat movements such as hand flapping, rocking or the repetitive use of an object such as twirling a pen or opening and closing a door. Autistic people often engage in these behaviours to help calm themselves when they are stressed or anxious, but many autistic people do it because they find it enjoyable.

Change to routine can also be very distressing for autistic people and make them very anxious.

#### Over- or under-sensitivity to light, sound, taste or touch

Autistic people may experience over- or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain. For example, they may find certain background sounds like music in a restaurant, which other people ignore or block out, unbearably loud or distracting. This can cause anxiety or even physical pain. Many autistic people prefer not to hug due to discomfort, which can be misinterpreted as being cold and aloof.

Many autistic people avoid everyday situations because of their sensitivity issues. Schools, workplaces and shopping centres can be particularly overwhelming and cause sensory overload. There are many simple adjustments that can be made to make environments more autism-friendly

#### Highly focused interests or hobbies

Many autistic people have intense and highly focused interests, often from a fairly young age. These can change over time or be lifelong. Autistic people can become experts in their special interests and often like to share their knowledge. A stereotypical example is trains but that is one of many. Greta Thunberg's intense interest, for example, is protecting the environment.

Like all people, autistic people gain huge amounts of pleasure from pursuing their interests and see them as fundamental to their wellbeing and happiness.

Being highly focused helps many autistic people do well academically and in the workplace but they can also become so engrossed in particular topics or activities that they neglect other aspects of their lives.

#### **Autistic Women and Girls**

In the past, it was assumed that autistic people were overwhelmingly men and boys, and only very rarely women and girls. This is wrong. There are many women, girls and non-binary people on the autism spectrum.

Although we now know much more about the experiences of autistic women and girls, society's understanding of autism has been limited by outdated stereotypes and incorrect assumptions. Although autism research and professional practice are slowly catching up to the realities of life for autistic women and girls, many barriers to diagnosis and support remain.

### **Does autism present differently in women and girls?**



#### **Extreme anxiety**

Anxiety is a real difficulty for many autistic people, particularly in social situations or when facing change. It can affect a person psychologically and physically and impact quality of life for autistic people and their families.

It is very important that autistic people learn to recognise their triggers and find coping mechanisms to help reduce their anxiety. However, many autistic people have difficulty recognising and regulating their emotions. Over one third of autistic people have serious mental health issues and too many autistic people are being failed by mental health services.

https://www.autism.org.uk/advice-and-guidance/professional-practice/anxietyparental



### **Diagnosing Autism**

Diagnostic manuals, ICD-10 and DSM-5, set out the criteria for autism to be diagnosed. These create the foundation for diagnostic tools such as the DISCO (Diagnostic Interview for Social and Communication Disorders), the ADI-R (Autism Diagnostic Interview - Revised), the ADOS (Autism Diagnostic Observation Schedule) and 3Di (Developmental, Dimensional and Diagnostic Interview).

The DSM-5 Manual defines autism spectrum disorder as "persistent difficulties with social communication and social interaction" and "restricted and repetitive patterns of behaviours, activities or interests" (this includes sensory behaviour), present since early childhood, to the extent that these "limit and impair everyday functioning".

In DSM-5, the terms 'autistic disorder', 'Asperger disorder', 'childhood disintegrative disorder' and 'Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)' have been replaced by the collective term 'autism spectrum disorder'. This means that it's likely that 'autism spectrum disorder' (ASD) will become the most commonly given diagnosis.



## Support

- National Autistic Society
- Kent Autistic Trust
- Kent Community Help
- Ambitious about Autism
- Autism South East
- Social Media/Forums