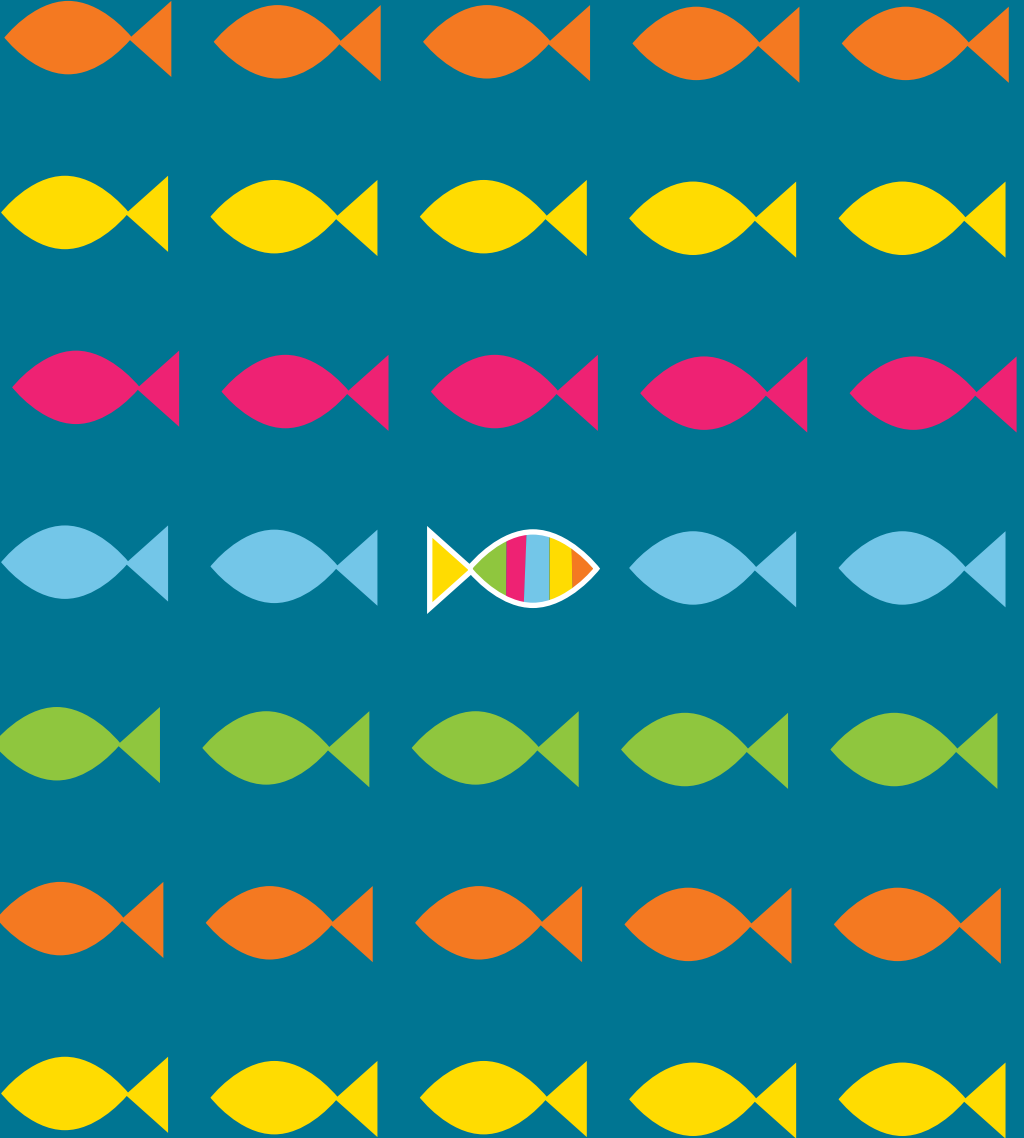


You are not alone

A parent's perspective on autism





Your child, is your child

It's difficult to say how you might feel when the suspicion starts to creep up that your son or daughter might be different in some way.

Or, it might be that the school or nursery is starting to share some concerns with you?

Perhaps some people are suggesting that you're not good enough parents? Maybe others think your child is spoilt or is naughty, or has a hearing difficulty?

For many parents, it can be difficult and painful to consider that their child may be different - and they feel anxious or guilty for feeling that way. For some, it's a relief to maybe have an answer as to why their child doesn't appear to be the same as others. Sometimes, it's a mixture of the two. These are common reactions and it's OK and natural to have these feelings.

Understanding how your child is 'wired' is a positive step.

But... however you feel about it, there's no question that the step between suspecting a diagnosable condition, and looking for a diagnosis, is a big one.

When should I seek help?

If your concerns are nagging and persistent - 'something isn't right - I know it' - trust your instincts. You are your child's expert and know them better than anyone else.

Think of it this way: whether or not your child has a diagnosable condition, seeking advice sooner rather than later could make it easier to access support and appropriate services.

Knowing what you're dealing with isn't the end of the road, it's the start of the journey - and at least it gives you a better idea of the direction to take.

Remember

As a parent, you are doing an amazing job. What is your norm, is your norm (we're all different!) That's true for everyone and that's OK. The most effective parenting is always tailored to the child - and for you.

What might make you think that it's time to ask for help?

Communication

- Being a 'late developer' with talking, either stalling or starting to lose speech skills at a time when other children's speech is 'exploding'.
- It's not unusual for children with autism to be suspected of hearing problems, when they can hear fine but just aren't responding.
- Difficulty understanding jokes, sarcasm and common figures of speech.
- Difficulty using and understanding gestures, facial expressions or tone of voice.
- Difficulty taking turns in conversations – talking across people.

Getting along with people

- Not knowing how to join in games.
- Alternatively, trying to make friends but not managing because their efforts seem 'off' to the other children.
- Difficulty grasping the idea of taking turns.
- Preferring to spend time alone rather than being with other children.

Social imagination

- Problems understanding and interpreting other people's thoughts, feelings and actions. May even appear to be insensitive.
- Difficulty predicting what will or could happen next, and needing repeated reassurance.
- Finding it hard to cope with new or unfamiliar situations, or needing help to prepare for change.



Sensory differences

- Being highly stimulated by certain visual experiences, or finding certain things extremely uncomfortable to look at, eg: flickering fluorescent lights.
- Finding certain noises unbearable, hearing sounds that others can't or, quite the opposite, might like noise and, for example, bang objects to make a loud sound.
- Being unusually insensitive to certain kinds of discomfort – for instance, having a high pain threshold, or not seeming to notice when it's cold or hot.

Emotional and behavioural

- Being overly anxious.
- Anxious feelings can also escalate very quickly if something triggers them and this can sometimes lead to a meltdown.
- Change is hard to deal with: certain things have to be done the exact same way each time or the child can become anxious and upset.

Of course, no child exactly fits a template; nobody does.

For instance, autism is a spectrum condition, which means it ranges from a child having subtle differences to being profoundly affected. Every person is unique.

What can you do?

Whether you decide to pursue a diagnosis, or wait to see how your child develops, here are some simple 'best practice' approaches that may help you to help your child on their way.

Set expectations

Clear rules and boundaries help a child to feel more secure, especially if they are struggling to read the 'unwritten' rules and sense the 'invisible' boundaries.

Visual Supports

These can help to provide structure and routine; also improve understanding and reduce anxiety. Types of visual support include photos, short videos, coloured pictures, drawings, symbols and written words. They should be durable, portable and easy to find. Lots of families keep a visual timetable pinned to the inside of their front door, a bit like this:



First and Then

Knowing the sequence of events is important to children, and it may help to reduce anxiety levels and reassure them if they know what will happen next, eg: 'First eat your lunch, then it's time to play with your cars'. Or 'When you have picked up your coat, then you can have an apple.' (this is also known as Future/Predictive language).

Do's work better than Don'ts

Tell your child clearly what you want them to do, eg: 'Hang your coat up on its hook', rather than 'Don't put your coat on the floor'.

What we pay attention to, is what we get more of

Encourage positive behaviour by giving praise and rewards immediately and in a way that is meaningful to your child, eg: verbal praise, a star chart etc. Some children will appreciate being praised for their effort (as they may never consider their work meets their own high standards).

Sensory needs

Some ideas:

- Allow the child to run around before a lesson or (at home) a visit from the relatives – to burn off energy.
- Allow the child to have a pillow or soft toy to squeeze – to stabilise anxiety (this is called proprioceptive stimulation – lots of people like to hug cushions when watching television).
- Do whatever works best, depending on your child's preference.

Giving information

Be concise and use short sentences, with one instruction at a time. For some children, a sentence like 'Put your coat away, come in, get your pencil case and sit down' is too many instructions in one sentence (It's 4 separate instructions! Quite a lot if you're only 5 years old).



what is autism?

Research has revealed that people with autism have brains that develop and function in a number of ways that differ to those without the condition. More than 1 in 100 people in the UK are autistic; the condition affects the way they interact with other people and how they experience the world around them.

Autism is a spectrum condition in that all autistic people share certain difficulties but that they will be affected in a variety of ways. Because autism affects different people in different ways, it can be more disabling for some than for others.

Also, it's possible for someone to appear more affected by their autism at different stages of their life. For instance, adolescence is a tough time for everyone!

Some people with autism will live independent lives, some less so. And others may face additional challenges, including learning disabilities, which affect them to such an extent that they need support in many areas.

“ If you’ve met one person with autism, you’ve met one person with autism. ”

Autism is never the whole story.

No one person has ‘textbook’ autism.

If you seek a diagnosis

Asking for a referral

If your child is very young, make an appointment with your doctor or health visitor.

If your child is school aged, make an appointment with the school's SENCO or Learning Support teacher to discuss your concerns.

For more detail on seeking a diagnosis, and what it might entail, please refer to:

NAS - All about Diagnosis

www.autism.org.uk/about/diagnosis.aspx

NHS - Autism Diagnosis

www.nhs.uk/Conditions/Autistic-spectrum-disorder/Pages/Diagnosis.aspx

Ambitious about Autism – How do I get a Diagnosis?

www.ambitiousaboutautism.org.uk/understanding-autism/diagnosis/how-do-i-get-a-diagnosis-

Source: National Autistic Society
www.autism.org.uk

Myths about autism

Is there a 'cure'?

No, there is no known 'cure' or specific treatment for autism. This does not mean, however, that nothing can be done to help. Our knowledge of autism has grown tremendously since it was first identified in the 1940s, and as we learn more about the condition and services continue to develop, autistic people will have more opportunities than ever of reaching their full potential.

Does autism just affect boys?

No, girls are affected as well as boys. It's still more common for boys to receive a diagnosis, but it's now increasingly believed that girls are better at masking their difficulties.

Don't all autistic people have outstanding abilities in one particular area?

No, although it may be true that some autistic people display skills in a certain area that can appear to contradict their apparent difficulties, so-called 'savant' abilities are very rare.

Don't autistic children grow out of it in adulthood?

No, an autistic child becomes an autistic adult, although the way their autism presents itself may change as they grow up.

On a positive note, autistic people:

- **Don't have 'hidden agendas' or play 'mind games'. What you see is what you get and what you hear is what they mean.**
- **Are generally honest, conscientious and reliable**
- **Often have the ability to focus long, hard and intently on the details of things and situations.**
- **And they tend not to be judgemental of other people...**

Common linked conditions

Some neurological conditions may also occur in association with each other – and any of these may be the main presenting condition. Professionals call these 'co-morbidities' (horrid terminology!) and some of them may include:

Autism

...causes difficulty with social communication

Dyscalculia

...causes severe difficulty in making arithmetical calculations

Dysgraphia

...inability to write coherently - just holding a pencil and organizing letters on a line is difficult

Dyslexia

...difficulty in learning to read or interpret words, letters, and other symbols, but that does not affect general intelligence

Dyspraxia

...causes difficulty in activities requiring co-ordination and movement

ADHD

...a condition that affects how well someone can sit still, focus, and pay attention

Mental health problems

...including anxiety, depression and obsessive-compulsive disorder



Where can I go for information and support?

**In the borough of Richmond,
you can talk to other parents here:**

NAS Richmond

T: 07810 505 982

E: Richmond@nas.org.uk

W: www.richmondnas.org

Express CIC

T: 020 8390 4273

E: info@express.org.uk

W: www.expresscic.org.uk

SEND Family Voices

T: 07469 746 145

E: sendfamilyvoices@outlook.com

W: www.sendfamilyvoices.org

South West London Girls Connect

E: swlondongirlsconnect@gmail.com

