

The Autism Spectrum

Produced by
The Surrey
Autism
Partnership
Board

for adults in Surrey

The Autism Act 2009 gave adults the right to an assessment that can lead to a diagnosis of Autism Spectrum Condition.

Increasing numbers of people are benefitting from a diagnosis, but many adults in Surrey remain undiagnosed.

Surrey Autism Partnership Board is made up of autistic people, family carers and professionals who help to develop information, support and community services for autistic adults in Surrey.

This magazine aims to improve awareness and understanding of both the strengths and difficulties autistic adults may have.



Surrey Autism
Partnership Board



Full of
useful
Information
to help you



Facts and figures to help people to develop their understanding of autism.



Personal stories and strategies to help people manage their lives.



Information about how to ask for a diagnostic assessment.



Introduction

From the Surrey Autism Partnership Board

Marianne Scallon and Tom Moore are co-chairs of the Surrey Autism Partnership Board.

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The main focus of this magazine is autistic adults, possibly not diagnosed, who may read this themselves and be able to implement the ideas or seek further information.

Some autistic adults have very severe difficulties. Their problems with communication, sensory sensitivities, coping with change and other issues, including possible learning disabilities, mean that they need a high level of support.

Most autistic people with difficulties of this kind will have been diagnosed in childhood and will be in contact with Surrey Social Services or the NHS Community Learning Disability Teams.

Frequently asked questions

How common is autism?

There are over 500,000 autistic people in the UK. That's about one in every 100 people.

There is also strong evidence to suggest that there are more men than women with autism.



What causes autism?

The causes of autism are still being investigated.

According to the National Autistic Society (NAS), there is strong evidence to suggest autism can be caused by a variety of factors which lead to the brain developing differently.

There is also evidence to suggest genetic factors play a role, and these genetic factors can be passed from parents to children.

What we do know is autism is not caused by the way children are parented.

Studies have also shown that vaccines like MMR do not cause autism.

How would I know if a person is autistic?



There is no 'typical' autistic person, it's a broad spectrum of people. For example a person may be a teacher, shop assistant, musician, engineer - or any other profession. People may keep their autism private for fear of prejudice.

It's important to note that a significant number of autistic people also have a learning disability, some of whom may need care and support 24 hours a day.

How can society become more 'autism friendly'?

Autism is not a disorder or illness to be treated or cured. Support should not aim to make people become less autistic, but help people to focus on using their strengths and developing strategies to manage their difficulties. Many autistic people prefer to view autism as a different, but equally valid, way of experiencing the world.

The aim should be to create inclusive environments, services and workplaces that accept and make allowances for people's differences, whilst enabling them to use their strengths.



The Autism Spectrum

In 2013 the term **Autism Spectrum Condition (ASC)** was introduced to cover and replace the conditions previously diagnosed, such as Autism and Asperger's Syndrome.

Why a spectrum?

Autistic people can be so different from each other that we think about autism as a spectrum, rather like a rainbow.

People of all abilities can have autism, including people with above average intelligence.

Strengths

There are many positive traits common to autistic people such as honesty, loyalty, attention to detail, original thinking, and good understanding of systems.

As we understand more, we are seeing how autistic people have excelled in many fields including sport, music, arts and science.

Uneven abilities

Some people have great skills and knowledge in their specialism, but struggle with everyday tasks like planning a meal or managing a new journey on public transport.

Interests and routines

Some people have a small range of, often solitary, activities which absorb them.

Many people like predictability and have set routines. Change can cause anxiety. Unstructured time, like holidays, can be stressful.

Some people find choice difficult. People may also have very fixed ideas and struggle to think about things in different ways.

Communication and social interaction

Autistic people can find other people's behaviour confusing. Many people want to be sociable but often find it difficult.

- People may find it hard to work out what other people are thinking and feeling.
- People often struggle to understand non-verbal communication like body language and tone of voice.
- People may take words literally. They can find jokes, irony and sarcasm hard to work out.
- People may struggle with small talk, not notice certain social rules and miss subtle hints.
- People may talk at length about a subject they are interested in.
- People may struggle to keep up with group conversations. They may take longer to process information and to phrase what to say. They can find it hard to tell when it's their turn to talk.
- People may feel overwhelmed by multiple instructions.
- People may struggle when 'put on the spot' and asked open questions like, how do you feel?
- People may state their opinions honestly and appear a bit blunt.

Some autistic people may not develop spoken language and need ongoing care and support.



A combination of the difficulties a person may have with communication, social interaction, interests, routines and sensory sensitivities are used to diagnose autism.

Other Common Issues

for people
with an

Autism Spectrum Condition



These are aspects of everyday living that autistic people may find a challenge.

People may not be affected by all of these issues, but they are common experiences for many.

The sensory world

Autistic people may be over or under sensitive in one or more of their senses. People may find it hard to filter out background visual stimuli, noises, and even smells. They feel they live in a more intense, amplified world.

Busy, noisy environments can feel like an assault on people's senses. Some people find they 'shut down' when overloaded.

People may prefer quieter social events with a few people to busy events like parties. There are some autistic people who rarely go out.

People may prefer an uncluttered home where they can control the levels of noise and visual input.

Some people may dislike certain tastes and textures. Many people find labels in clothes irritating.

Organising yourself

Some people may find it hard to organise themselves to meet deadlines at work or college.

Other people are meticulous planners making them effective, reliable workers.

Anxiety

Autistic people often find the world a confusing place where the rules, and people, are not consistent.

People often like things to be correct and certain. This can lead to high levels of anxiety.

Many people find it hard to relax. They are always on alert trying to make sense of the social rules and the meaning of what people say.

People may worry constantly about 'getting things wrong' when they interact with other people.

Their mind can just keep going over the same thing again and again. It can be exhausting. Socialising can be very tiring for many people.

In difficult situations people may panic and struggle to think of what to do to get themselves out of it.

People may find it hard to tune into their own emotions. They may not realise that they're anxious until it overwhelms them and they lose the ability to make decisions or even communicate their needs.

Attention to detail

People may show great attention to detail, whilst sometimes not being aware of the 'big picture'.

E.g., a person may remember exact dialogue from a film but not quite 'get' the subtleties of the plot.

Good attention to detail is an asset in many fields of work.

Mental health

High levels of anxiety can lead to people needing the support of mental health services, who need to have a good understanding of autism.

This will help to avoid difficulties people may experience due to their autism being misdiagnosed as other mental health conditions, and being given the wrong support or treatment.

Stigma

Many autistic adults describe how they always felt 'different' and as children experienced being bullied or excluded.

These experiences can continue into adult life and have a significant impact on a person's self esteem.



Diagnosis

for adults in Surrey

The Autism Act 2009 gave adults the right to an assessment which can lead to a diagnosis.

In recent years the diagnostic criteria have been widened.

More adults are now being diagnosed, especially adults who do not have a learning disability. However, there are still a significant number of undiagnosed adults.

There is no simple 'test' for autism.

The diagnostic criteria focus on:

- Social communication and interaction.
- Restricted, repetitive behaviours, activities and interests. Sensory sensitivities.

It needs to be clear that a person has been autistic their whole life.

How to ask for a diagnostic assessment in Surrey.

Talk to your GP if you think you may benefit from a diagnosis.

They can refer you to the Surrey Neurodevelopmental Service.

When it is your turn to be seen by the service you will receive a letter inviting you to a meeting with an autism specialist who is supervised by a Consultant Neurodevelopmental Psychiatrist.

You will be sent questionnaires to fill in and bring to the meeting.

The meeting with the autism specialist lasts for two to three hours.

Having a diagnosis can help people to understand themselves better and enable them to find strategies to help manage their day to day lives.



Howard Childs is an autism specialist working for Surrey Neurodevelopmental service.

We try to help people feel relaxed when they come for their diagnosis meeting. It helps if they can come with someone who has known them since childhood.

Age is no barrier to diagnosis, we've diagnosed people aged from 18 to 80.

We can usually tell people if they have an Autism Spectrum Condition at the meeting. People are sent a report about their diagnosis and will be invited to a Post Diagnosis Course.

At the course they can learn about their diagnosis and find out about support that is available locally.

When the diagnosis is unclear, or extra understanding is needed, our Further Assessment Team can provide a more in-depth assessment.



I was diagnosed with an Autism Spectrum Condition in 2015

I'm an autistic person, not a person with autism - It's not something you can catch!

I describe autism as my superpower. I'm brilliant with patterns and combinations. I have a fantastic memory for codes and phone numbers. I can remember every phone number I've ever had - even the first one when I was 3 years old.

I've always thought differently and see solutions others can't. I have great attention to detail. I've done a range of jobs from sales to standup comedy. I now work as a DJ as well as building websites and search engine optimisation.

I was always the naughty kid at school, I couldn't focus. I was happy out on my bike on my own. I'd tag along with other kids, but was always on the outside. I knew I was different when I was a kid, but I didn't know what it was.

Two of my children are diagnosed with autism and I noticed more similarities between me and them. At dinner I eat everything in order, never mixing things. I'm really sensitive to noise and can't bear the tags that clothes have in them.

My wife flagged up that I should see if I was autistic. I was struggling a lot at the time going into meltdown mode often.

My brain doesn't switch off, things keep going round and round until I just can't think anymore and get total brain fog.

I then spend hours in bed with a pillow wrapped around my head to shut everything out.

Getting the diagnosis was just the start. I've begun to analyse my life. Looking back I can now see myself as an autistic kid rather than a naughty kid.



Strategies for Living Your



Using your interests and being yourself

People can become very skilled and knowledgeable about their interests. Being absorbed in their interest can be a person's best way of relaxing.

Many people accept that it's okay to be different. They choose not to put so much value on things others see as important, such as the approval of others or social gatherings.

Advanced planning for situations

Practicing for situations like a job interview can be helpful. People may not spontaneously think of things to say or questions to ask, so having a list can help.

Some people like to practice a new journey before they need to make it for real.



Learning social skills

Many autistic people don't instinctively pick up unwritten social rules. For example, not using your mobile phone when in a meeting at work.

People can learn to work out these 'social skills' over time, often with support. It can help to explain social rules by writing them down.

Extra stimulation

Some people find extra stimulation helps them to relax and focus. For example, having something to fidget with, like putty, can help people to concentrate.



Crisis plan and calming activities

Carrying a crisis plan, with a written list of instructions to follow, such as who to phone and what to say, can help in situations when a person may panic and struggle to think what to do.

Some people carry a list of 'calming activities' to choose from when they feel anxious.



Autism Alert Card

It can be useful to carry an Autism Alert card.



Surrey Police have developed the free Pegasus Card. As well as being an alert card you can register the support you need with the Police so they can give you the right help if you need them. Phone 101 to ask for a Pegasus Card.

Communication

Many people learn to work out how other people think and communicate.

This can be a painstaking process as people build a reference library in their mind of what different sayings mean.

Some people benefit from using pictures to help them communicate their needs.

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Visual supports

People often find visual information easier to process than verbal. Making written lists helps memory as well as prioritising to do things in the right order.

Calendars and diaries allow people to 'view' events and help to make things more predictable.



Rest and 'time out'

Managing social situations can be very tiring. People can be constantly on alert trying to 'fit in' with others.

Autistic people may need more rest and time alone, simply to allow their mind to process the day's events.



A 'safe place'

Some people have a 'safe place' they go in their home to escape.

Others know not to disturb them.



The right environment



The right environment for a workplace is very important.

A busy open plan office is some people's worst nightmare.

People may struggle to focus and find the background noise and distractions exhausting.



Social media and email

Communicating with people via social media and email can be a useful strategy as you don't have to respond to messages in 'real time'.

This gives people time to work out meanings, compose a reply and edit before sending.

Structured activities

Many people find structured activities with a clear beginning and end easier to manage than unstructured activities like a party. With parties it's not always clear what time to arrive, leave and what to do in-between. Having a defined role at a social event can also help people feel a sense of control.

Reasonable adjustments

Under the Equalities Act 2010 services need to make 'reasonable adjustments' to enable autistic people to have the same level of service as others.

In practice a reasonable adjustment is things like a hospital giving an autistic person the first appointment of the day if they struggle to cope in a busy waiting room.



Shutting out distractions



Some people find using earplugs or headphones helps them shut out background distractions, allowing them to focus on the task in hand.



The Autism Champions Network.

Autistic people in Surrey have identified that they need services to have expertise and understanding of autism.

The Autism Champions Network has been set up in response to this. The aim is to be a countywide network of expertise. We aim to train at least 80 Champions across a range of organisations in Surrey.

Email: ldcommunications@surreycc.gov.uk

Autism websites



The Surrey Autism Partnership Board

Local news, information, events and support.

Website: www.surreypb.org.uk

NAS Surrey Branch

Useful information, news and events.

Website: www.nassurreybranch.org

The National Autistic Society (NAS)

Information, advice and support.

Website: www.autism.org.uk

Other useful websites

www.surreyinformationpoint.org.uk

A directory of local information and support.

www.surreycc.gov.uk

The website of Surrey County Council.

www.surrey.police.uk

The website of Surrey Police.

www.NHS.uk

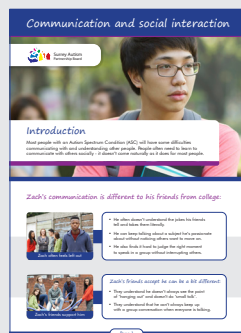
The website of NHS Choices.

www.sabp.nhs.uk

The website of Surrey and Borders Partnership NHS Foundation Trust who provide mental health and learning disability services.

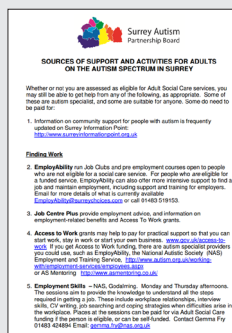
Useful factsheets

You can download our factsheets from the website of the Surrey Autism Partnership Board (see above).



Our 7 information factsheets

1. Introduction to autism.
2. Diagnosis.
3. Communication.
4. Useful strategies for life.
5. Social care and community.
6. Health services and support.
7. Our stories.



Our local support/services factsheet

This factsheet was produced by the Surrey Autism Partnership Board.

It gives information about a wide range of support that is available for autistic people in Surrey.

This includes advice services, advocacy and support groups.