

Chapter 1

Introducing Asperger's Syndrome

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When people first hear about autism or Asperger's syndrome (AS), they often think about the film *Rain Man* — the one in which Dustin Hoffman's character could memorise all the numbers in the phone book and do difficult maths in his head really fast. Some people on the autism spectrum have these amazing abilities, but not all. In fact, only about one in ten people on the spectrum have a so-called *savant skill* — an incredible ability in a particular area. Misconceptions like “all people with autism have an amazing skill” are some of the false impressions of AS we deal with in this chapter.

One thing about *Rain Man* that was quite an accurate portrayal of the autism spectrum was the character's dislike of change. He liked to stick to his routines and know what was happening when, and had certain obsessive interests. He also found social interaction hard to understand and sometimes had difficulty communicating. So the film covered some of the key characteristics of the autism spectrum: dislike of change, obsessive interests, difficulty with social interaction, social communication and social imagination.

In this chapter, we introduce you to AS as part of the autism spectrum. You can find out how it was discovered, what life with AS is like and how AS is diagnosed.

Describing What Asperger's Syndrome Is Like

Describing a person with AS at key stages in his or her life is probably the best way to explain the condition. We've invented a fictional character here (called Robert) to help you understand what life is like from the perspective of someone growing up with AS.

Robert as a young child

Robert didn't like being cuddled as a baby. He didn't really enjoy playing peek-a-boo with his mother and didn't smile very much. However, the rest of his development was fine: he learnt to both walk and talk at the right times. In fact, he was really good at language, often using really complicated words that were advanced for his age. Robert was interested in light bulbs as a young child. He learnt the names of each brand and each type of bulb, and had an extensive collection in his bedroom. He could talk about his collection for hours to whoever would listen! Robert didn't play with other children at nursery school. He preferred to draw pictures of light bulbs on his own, rather than join in with games. At this age, Robert also hated the noise of the vacuum cleaner. His mum had to wait until he'd gone to nursery before she could do the hoovering.



People on the spectrum are often extremely sensitive to sensory stimuli; sudden noises, for example, can be a particular difficulty, as can bright lights and certain smells. For more on senses and autism spectrum conditions (ASCs), go to Chapter 12.

Like anyone, Robert found changes in his life stressful. And some changes he seemed to find much more stressful than most people did. High stress levels can make anyone suffer and retreat into the safety of routine, and very small children displaying some rigidity which they then grow out of is completely normal. When Robert and his parents moved house, everyone found the experience very stressful. Robert's stress, however, was something special: he wouldn't come out of his bedroom for days, he made even less eye contact than usual and his hands shook continuously. His desperate need for routine and safety may have started here. His parents had to make sure he got up at 8 a.m. every day, got dressed at 8.05 a.m., brushed his teeth at 8.10 a.m., had toast and jam for breakfast (using exactly the same plate, knife and fork and eating the same brands of bread and jam), and so on. If anything had to change for some reason, he'd throw a really big tantrum.



Routine is very important for some people on the spectrum. If you're a parent looking for more information on routine, see Chapter 9.

Robert at school

Robert was bright, so he went to a mainstream primary school. He enjoyed learning but really struggled with break and lunch times. He'd often hit and kick other children who wanted to join in with what he was doing. He'd spend a lot of time standing at the edge of the playground, walking along the lines marking out the football pitch. This habit often got him into trouble when other children were playing football! Robert was still really interested in light bulbs and would switch the school lights on and off when he could, to see how the lights flickered. He was often in trouble with the teachers.



Break and lunch times can be particularly difficult for children on the spectrum. Teachers may need to provide extra support during these periods or provide alternatives to going out in the playground, such as going to the library or a quieter, less busy area of the school. For more information on school and AS go to Chapter 11.

At secondary school, Robert became fascinated by history, particularly the world wars. He memorised lots of facts, details of uniforms and dates of battles. In fact, his history teacher used to get quite cross with him because he'd shout out the answers to every question she asked in class. He didn't give the other students a chance to answer. Robert got bullied a lot at secondary school because he was different. Bullies pick on people who don't have friends because no one tries to stop them. Robert wasn't interested in girls and didn't relate to the social chit chat teenagers enjoy. He didn't understand why the other students would spend ages chatting at break and lunch time instead of doing something constructive like maths or reading about the Second World War in the library. He had one friend with whom he played card games, but the other children didn't like him because all he'd talk about was world wars. Nevertheless, Robert did well at school academically (though he did struggle with English literature and foreign languages) and got a place to read history at university.



People with AS aren't intellectually impaired. They may be of average intelligence like the rest of the population, and some people with AS are exceptionally bright.

Robert as an adult

At university, Robert wanted to make friends and have a girlfriend, but didn't know how. He liked one girl and so followed her to all her lectures, but the girl got cross and told him to leave her alone. Robert became miserable, because he hadn't made any good friends, and he wasn't enjoying lectures. Though he loved history, there were too many people in the lecture hall. Someone would always be coughing, which was a noise he couldn't stand, and he found it difficult to concentrate on what the lecturer was saying because of the traffic noise outside. Other people in his classes teased him because he'd always wear the same T-shirt (it felt nice, and didn't scratch his skin). He often couldn't tell when people were being friendly or not, because he couldn't recognise their facial expressions very easily. Robert struggled to get his work done on time, and ended up spending more and more time alone in his room. His parents became concerned and took him to see a psychologist to determine whether he was depressed. At this point, Robert was diagnosed with AS.



You can be diagnosed with AS at any age. You have the condition all your life, but people may not realise it until you're older. For more information on diagnosis, see Chapter 3.

Having a diagnosis of AS opened the door to some support at university for Robert. He was assigned a mentor, who helped him with lecture notes and organisation. His mentor also took him along to the pub, where he began to get to know some other people in his year at university. In his final year, Robert felt much better. He left university and got a job in a library. Unfortunately, things got worse again. Robert received no support at work, and his boss was always cross with him for not being flexible enough and not dealing well with the people using the library. In the end, Robert had to leave his job. He was still living with his mother, who organised all his bills, meals and clothes.

Now, Robert is 30 and his mother is still looking after him. He has a part-time job as a library catalogue assistant, and attends some social groups run by a local charity, but his mother is worried about what will happen when she's no longer able to look after him.



Robert isn't a real person, but his story includes many facts that are common features of AS. You may find this brief description of what AS is like useful in relation to your own life or that of someone you care for.

Recognising the Characteristics of AS

Unusual behaviour is characteristic of people on the autism spectrum (see the previous section on our invented character, Robert). The autism spectrum applies to people who have difficulty with social communication, social interaction and social imagination.

We used the word *social* a lot in the previous sentence because the social aspect of ASCs is thought to be the most important in diagnosing them. We live in a very sociable world in which people often talk about the weather just to have something to say to each other. If you're asked, "How are you?", you should always reply "Fine, thanks!" even if you're feeling really unwell. Unwritten social rules and social expectations are widespread in our society. If a pause occurs in conversation, people fill it with chit chat about the weather, even if they aren't particularly interested in the weather. People ask other people if they're feeling okay out of politeness, rather than because they really want to know the true answer. These sorts of social niceties are often a mystery to people with AS. In fact, many people with AS have to learn such things by rote, if they're able to learn them at all.

If you have AS, you may have difficulties with the following things:

- ✓ Understanding social interactions, social rules and social expectations
- ✓ Recognising other people's feelings and emotions (by their facial expressions, tone of voice, or body language and gestures)
- ✓ Making friends and keeping friends, even though you may want to have friends

- ✔ Making conversation (knowing when to start or end a conversation and what to talk about)
- ✔ Understanding jokes, sarcasm, idioms and metaphors (you may take language very literally)
- ✔ Figuring out what other people are thinking (you may find other people confusing and unpredictable)
- ✔ Imagining alternative outcomes to a given situation

All these difficulties can make life a struggle for people with AS. More than half a million people in the UK have an ASC. That figure represents at least one in 100 people trying to get to grips with the very sociable world we live in. Our society can be very confusing and frightening if you don't understand it and can't predict what's going to happen next. People on the spectrum may not seem to be very interested in people and may withdraw from society altogether. This withdrawal isn't surprising — imagine having to work out what other people are thinking and feeling all the time. You may not have to imagine this scenario — it could sound very familiar to you.

Considering Other Aspects of AS

As well as the difficulties with social interaction, social communication and social imagination, people with AS have other characteristics that can make their lives tricky, as described in the following sections.

Sensory issues

People on the spectrum often have sensory sensitivities or insensitivities. For example, the label in the back of your shirt may feel painful on your skin if you have a particular sensitivity to touch. You may wear very tight clothing in order to feel “properly” clothed if you're insensitive to pressure. The noise of a vacuum cleaner, a baby crying or a dog barking may hurt your ears. The smell of perfume may make you feel sick. Simultaneously, some sensory input may be really attractive for you, like a fan spinning around or patterns of flickering lights. Imagine having to walk down a street being bombarded by smells, noises, lights and feelings when your senses are overloaded by the experience, and then trying to “act normal” among the people around you. You can find out more about sensory sensitivities in AS in Chapter 12.



If someone with AS wants to wear open-toed sandals and shorts in the winter, you should let them. They probably want to do that because socks and trousers make their skin feel sore, or they get too hot — yes, really!

Routines

Living in a world that you can't predict, where you can't figure out who's going to do what and when, and where sensory information is distracting, painful or overwhelming is going to make you feel stressed out. Many people with AS rely on maintaining strict routines in their lives to make more sense out of it and to have some control over what's going on. People with AS may get upset if the routine they were expecting doesn't happen. Many parents do their utmost to create order and predictability for their child with the condition.



While people with AS often need some predictability and routine, learning that things may not always work out as planned is important. If you're a parent of a child with AS, allow your child to have the routine that he or she needs, but also try to teach flexibility from time to time. See the nearby sidebar "Choosing your weapons and your battleground carefully".

Special interests

Many people with AS have special interests. For our character earlier in the chapter, Robert, it was light bulbs and the world wars. The Goth is particularly interested in psychology, physics, linguistics, gait and poise (how people stand, walk and move), history, art, archaeology, Formula One, walking (in the countryside), maps, cricket and the autism spectrum. Not to mention the interconnections between these things! People with AS often become highly expert in a particular area such as train timetables, fossils, fashion or hairstyling (your culture tends to influence what subjects you become interested in — you can guess which of these are usually picked by boys and which by girls!). People on the spectrum may find understanding that other people may not be as interested in the things they are difficult, and may talk incessantly on the same subject without realising the person they're talking to is bored.



Special interests may take over a person's life, but don't try to stop someone from pursuing his or her interests altogether, just encourage the person to do something else some of the time. A special interest may provide a person with opportunities or even a career in the future.

Looking into the History of AS

The term *Asperger's syndrome* was first used in 1981 by Dr Lorna Wing, an expert in the autism spectrum. She drew attention to a paper written by Hans Asperger in 1944 which described people with the social, communication and imagination difficulties we talk about earlier in this chapter. To understand a bit about where the different diagnostic labels on the autism spectrum come from, you need to know a little bit about the history of Hans Asperger and another doctor, Leo Kanner.

Choosing your weapons and your battleground carefully

When the Goth was three and learning to use cutlery, he found it too difficult to use a fork in his left hand. The Goth's parents are very old-fashioned and felt that using a fork right-handedly was incorrect, so they tried to insist that he eat "properly". After several weeks and many, many tantrums, they gave up and allowed him to use his fork in his right hand and his knife in his left.

The Goth's parents used an old set of cutlery given to them by a relative. It was incomplete, and some of the knife handles had been damaged by hot saucepans and other accidents over the years. The dinner knives were larger than the side knives, so the children used side knives because they were easier for their small

hands to manage. Only three side knives were left in the set, two of which had damaged handles. The Goth tried to insist on always using the "perfect" one, but while his parents eventually saw the reasonableness of using cutlery left-handedly, insisting on a particular knife was just not reasonable. The Goth tried to compromise by agreeing to use either the perfect one or the butter knife (of which there is only one in an old-fashioned cutlery set – the one with the serrated tip for scraping the butter off the rock-hard pat). This behaviour was still unreasonable. For some reason, the Goth didn't fight hard over this one, so having got used to the feel of the different handles, after quite a few tantrums he used what he was given.

Introducing Hans Asperger and Leo Kanner

Leo Kanner, an Austrian doctor working in America in the 1940s, was the first person to describe a group of children who shared a set of characteristics we now call *autism*. These children preferred to be alone rather than with others, liked playing with objects rather than other children and had problems with language. Kanner coined the term *autism* because it suggested a desire to be alone (*autos* means *self*). Children described in Kanner's paper had a desire to do the same thing over and over, and were quite rigid in their routines.

During the same period, Hans Asperger, another doctor in Austria, published a paper describing a group of children whom we now recognise as being on the autism spectrum too. These children found it hard to make friends, had one-sided conversations and had intense special interests that they could talk about for hours. Unlike the group Kanner described, Asperger's children didn't have difficulty with language and spoke fluently (they often resembled little professors as a result of the advanced language they used and their incredible knowledge about their favourite topics). No one in the English-speaking world took much notice of Hans Asperger's 1944 paper, because it was published in German. Not until Dr Lorna Wing drew attention to his

paper did people start using the term Asperger's syndrome. The paper was then translated in 1991 so that people in English-speaking countries could read about Hans Asperger's work.

Nowadays, experts in ASCs argue about the differences between the diagnoses of high-functioning autism and AS. Many say that no difference exists between people with these two diagnoses; others think they are different. Arguments about diagnostic categories continue to this day, and, in fact, a new version of the diagnostic manual for doctors, due out in 2013, will include a revision of the different ASCs. Chapter 3 covers diagnosis.



Whatever your or your child's diagnosis, always remember that each person is an individual and will be different from the next person. No two people on the autism spectrum are the same. Each person's needs and interests will vary.



Whenever we say "you" or "your child" we mean "you or your child" — repeating the whole phrase each time would just be clumsy.

Understanding autism as a spectrum

You'll come across the term *autism spectrum* quite a lot when researching AS, so it's probably worth us spending a bit of time explaining what the autism spectrum is and where AS fits on it. Asperger's syndrome as a label was suggested after that of autism. *Autism spectrum conditions* is a term used to describe all people who have difficulties with social communication, social interaction and social imagination. The autism spectrum contains lots of labels, one of which is AS.

The concept of autism as a spectrum was first developed by Dr Lorna Wing, who has since worked extensively on autism and published many important research papers. The word *spectrum* implies some sort of variation, and indeed people can vary in their difficulties or abilities regarding any of the characteristics associated with ASCs. The term AS is used for people at the more able end of the autism spectrum.

If you have AS, you don't have a learning disability like many people at the lower end of the autism spectrum do (*learning disability* is when a difference exists between someone's expected performance, given their intellectual ability, and their overall achievement at school). Specific learning difficulties such as dyslexia, dyspraxia and dyscalculia (problems with reading, co-ordination and arithmetic) do affect people with AS, though, and all people on the spectrum have non-intellectual learning disabilities (sometimes called social disabilities or social learning disabilities). These non-intellectual learning disabilities mean people on the spectrum find learning the meaning of body language, facial expression and tone of voice very difficult. Some also struggle with face-blindness, which means they find it hard to recognise people from their faces.

Most people with AS have average or above-average intellectual ability. They're also usually highly able to communicate using the spoken word. Some people with AS, however, may not talk out of choice — called *elective mutism* — and some may talk less because they're not sure how to make conversation. In contrast, people on the lower end of the autism spectrum may not be able to talk at all, or may only speak in phrases. Some may communicate using symbols or express themselves by writing things down rather than using words.

These days, experts in autism like to describe ASCs as a “landscape” rather than a “spectrum”, because a landscape allows for variations across many dimensions, not just one. But we'll stick to autism spectrum conditions for now (autism-landscape conditions just sounds a bit odd!). For more information on the diagnosis of ASCs, go to Chapter 3.

Looking at Where We Are Today

Researchers, parents and people with ASCs themselves have been trying to understand the causes and characteristics of ASCs for years. Thankfully, professionals have moved on from diagnosing children as being “retarded” or “emotionally disturbed”, but we still need to study more and hear more people's stories to understand autism and AS fully.

Understanding the changing prevalence of autism

Twenty years ago, very few people had heard of autism spectrum conditions, let alone AS. Now they're much more widely recognised, and everyone seems to know someone who has an ASC or at least to have heard of it. Recent estimates suggest that about one in 100 children in the UK has an ASC. When you apply that figure to the whole UK population, it means over half a million people in the UK have an ASC (not all of these people will have a diagnosis though). More males than females have an ASC, and this is particularly true in AS, where the ratio is officially about 7:1. For more on the gender ratio, see Chapter 3.

You've probably noticed suggestions in the media that ASCs are on the increase. Many people blame lifestyle changes, vaccinations and other environmental factors for this rise. However, so far the evidence hasn't found any of these things to have caused an increase in ASCs. The truth is probably that ASCs are now more recognised, so more people are getting diagnosed as a result of this increased awareness. Studies all over the world have found roughly the same proportion — one in 100 — even though different countries

use different vaccines (or even no vaccines), eat different diets, get different amounts of vitamin D, and expose their citizens to different levels of pollution. These differences imply that none of these things can have caused ASCs.



People with AS come from all backgrounds, religions, countries and cultures. The increase in prevalence of ASCs is a challenge for schools and service providers. The fact that more people are getting diagnosed means that more people should have access to the education, support and services that they need. We just need the system to keep up!

Correcting Misconceptions about AS

Here are a few myths and misconceptions about AS that we'd like to clear up.

If you have AS you're a genius like Rain Man

You may be extremely clever. You may have a special talent (say, in music, maths, memorising data or chess). However, not everyone with AS is a genius or has an amazing talent. People with AS can just be normal people too!

If you have AS you're stupid

This is certainly not true! Current diagnostic criteria mean that to get a diagnosis of AS you must be of average intelligence or above. Having a diagnosis of AS means you don't have significant intellectual impairments — that is, you aren't stupid (although you may have specific problems such as dyslexia or dyspraxia). You are at least average, and may be very bright indeed.

AS is the parents' fault

AS is definitely not the result of something the parents have done, or the fault of the person with AS. AS is the result of a difference in genetic make-up that makes the brain develop differently, resulting in the characteristic behaviours of AS. Parenting has absolutely nothing to do with the cause of AS, although good parenting can help children with the condition develop their skills and cope with their difficulties. You can read more about parenting in Chapters 9 and 10.

If you have AS you don't have feelings

False. Feelings and emotions affect people on the spectrum just like anybody else. You may have trouble recognising these feelings in yourself and in others, but that doesn't mean the feelings aren't there. You may feel that your emotions are so overwhelming that you *can't* express them. Or you may have trouble expressing them, often needing time for the emotions to come out. See the nearby sidebar "Merry Christmas! I hope you like it!"

Merry Christmas! I hope you like it!

One of the things the Goth hates about Christmas is receiving presents. He knows that he's expected to thank the giver warmly and look happy with the gift. "Oh, yes," you say, "everyone hates trying to look pleased when they get a present that they don't like."

But the Goth's problem is that he can't look pleased when he gets a present that he *does* like. Typically, he needs to sleep and then he can feel how happy he is to have been given the present. He doubts that he's ever managed to convince anyone that this is true!

If you have AS you can't empathise

False. Empathy between people attending social groups is visible at every social group. It's people who aren't like you that you have trouble empathising with. And that's true whether you're on the spectrum or not.

If you have AS you don't need friends

Human beings are social animals, and that's true of everybody. However, many people on the spectrum enjoy their own company more than that of others. This doesn't mean that they don't need or want friends though. Many people with Asperger's are lonely and need help making friends, but they need friends just as much as anybody else does.

AS makes you violent

You have to put up with a lot when you're on the spectrum. Daily life is more frustrating, stressful, nonsensical and infuriating than for most people. Unusual reactions to these pressures, such as shouting, meltdowns (see Chapter 6 for more on these) and banging your fist in frustration all get classed as "violent outbursts", and because of a tendency to be less concerned about what other people think, and because of the pressure people on the spectrum are under, they do these things more often, and so may seem more violent. But anyone would do these things when under enough pressure. Genuinely violent behaviour such as fighting or attacking someone with a knife is no more common in people with AS than in people in general.

If you have AS you won't ever get married

All the talk of a lack of social skills and a preference for objects rather than people suggests that people with AS won't ever form meaningful relationships. Again, this is a myth. People with AS often really want to make friends and are perfectly able to keep friends; many go on to get married or have a meaningful romantic relationship. Lots of people with AS struggle with this side of their life, though, and making sure they get the right support to work out how to make and keep friends is important. You can find more information about this in Chapter 11.

If you're able to make eye contact, you don't have AS

This is another misconception, because some people on the spectrum can and do make eye contact. Other people find looking at someone else's eyes painful, so won't do it. Some people learn to make more eye contact or work out strategies to cope with eye contact, such as looking at the side of the person's nose. Someone who makes eye contact can still have AS.

AS is something found in children not adults

Nope — AS is a lifelong condition. Often AS is diagnosed in childhood, but these children grow up into adults and they still have AS. Many adults have AS but don't get diagnosed until later on. This situation arises because AS is more widely recognised now, so people who are older may not have had the support or options for diagnosis when they were growing up.

If you have AS you're good with computers

People tend to notice unusual talents, and to most people computers are a bit of a mystery. Also, programming computers doesn't involve social interaction and follows rules, some of which are subtle and have to be puzzled over. So a disproportionate number of computer programmers have Asperger's — and an eye for detail and perfectionism tend to make Asperger's programmers among the best. Add to this detail the fact that computers have become hugely important and commonplace in the last 20 years, and everyone sees lots of people with Asperger's using computers (even though we've moved on from the days when you had to program your own). But you'll still only learn to be good at computers if you're interested in them.