

Understanding Autism

A handout for support workers and personal assistants



Around one in 100 people are on the autism spectrum

This figure comes from The National Autistic Society.

Autism alert cards



Some autistic people carry an autism alert card. A person may use this to alert others when they are feeling overwhelmed and finding communication difficult.

Alert cards can be found on The National Autistic Society website. Search for 'alert card' at www.autism.org.uk

Some autistic people may use a different alert card, or a sunflower lanyard.

People of any gender can be autistic

Autism is a lifelong condition, and autism in girls and women is more likely to be missed, or misdiagnosed.

Some autistic people have a learning disability and some do not

Mencap estimates that about 50% of autistic people also have a learning disability, however, people of all intellectual abilities can be autistic.

Some autistic people use the term Asperger Syndrome which was an official diagnosis given until 2013.

Strengths and challenges

In this handout we will explain about the common strengths and challenges autistic people may experience. Not every autistic person will experience all of the strengths and challenges we describe.

Supporting people

Whilst some autistic people lead independent lives, others may need support. Different people will need different levels of support, ranging from just a few hours a week, to 24 hours a day.

There is no such thing as a typical autistic person

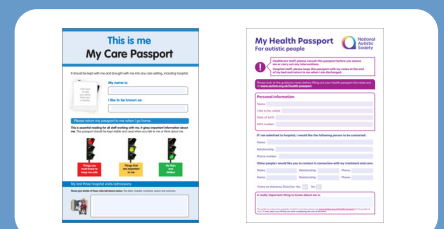
Issues such as sensory differences, communication differences and anxiety can have a greater or lesser impact on the lives of different autistic people.

"If you've met one person with autism, you've met one person with autism." Dr. Stephen Shore

Health and Care Passports

These outline a person's communication, support and health needs to staff in any medical setting. They reduce the need for lots of questions to be asked.

They are free to download. Go to www.surreypb.org.uk for the traffic light version for people with a learning disability. Go to: www.autism.org.uk for the autism health passport - search for 'health passport'.



Getting to know me

My interests

I may have specific interests that I'm really passionate about. Take time to talk to me about my interests. This is a great way to get to know me.

I may like to talk about my interests a lot!

Be warm and open

I might like to hear about your life, to get to know you as a person.

It's then much easier for me to build trust with you.



Treat me like an adult

I may well be as intelligent as you (or even more intelligent!). Just because I'm autistic, people sometimes talk to me like I'm a child, which is really annoying.

Try to be reliable

Let me know if you're running late, or I may panic and get really anxious. Let me know if you can't do what you said you would. I like things to be certain.

Getting to know my strengths



I may have a really good eye for detail

Many autistic people do, and can be really good at tasks like proofreading, maths and computer programming.

I may be able to concentrate on an activity for long periods of time - as long as it's really interesting of course!

I'm likely to be a terrible liar!

It's common for autistic people to be very honest and upfront. Autistic people are often very reliable too, and are likely to have a strong sense of fairness.

I may have uneven abilities

There may be things I'm brilliant at, things that just come naturally to me, such as learning facts.

I may be described as 'high functioning', but this doesn't mean I won't need support at times.

However, there may be things I really struggle with that might seem easy to you, such as planning an unfamiliar journey, organising things at home, or telephoning someone to book an appointment.

I may be good at logical things

Some autistic people have an instinct for solving logical problems and understanding how systems work - fixing computers is one example.

There may be things I'm expert in

I may be really knowledgeable about specific things that I'm passionate about. This expertise may be useful in my studies and in employment.

Help me use my strengths

I may not always value my strengths. If I find something easy to do, I might assume everyone else does too.

I may need support to use my strengths in my daily life, and in the workplace.

I may have a different communication style to you

I may not always pick up on body language

I may struggle to read facial expressions, and to pick up on your body language or tone of voice.

If you tell me you are fine, I might assume you are fine, even if you said it in a grumpy way.

I may find eye contact really intense

I may struggle to process what someone is saying if I look them in the eye. I may find it easier to listen when I'm looking away.



I may struggle to read between the lines

I might not always pick up on hints. For example, if my lawn needs cutting just tell me rather than saying "the grass is getting long". If you say something like "I'll get him to call you", I might assume you'll speak to him straight away, when you might mean you'll leave a message on his desk for when he's next in the office.

The way non-autistic people communicate can be really confusing at times !

I may seem a bit blunt sometimes !

By being direct and honest I may come across as rude without meaning to be.

I may have very fixed opinions about certain things, and at times struggle to see other people's point of view.

Moving around may help me to focus

I might find it easier to listen if I'm able to have something to fiddle with, or I am moving in my chair. Some people find that trying to sit still takes up all their concentration, and they're not able to focus on what anyone is saying.

A few tips to help with communication



Some people may not communicate using speech

Some autistic people may use Makaton signing, or even communicate how they are feeling through how they behave, such as getting distressed in a busy place.

Give me time

It may take me longer to process information, and to understand what other people are saying. Try not to talk too quickly, whilst not sounding patronising !

I may need to ask lots of questions to make sure I've understood. Writing things down often helps. Written information is permanent, so I can process it in my own time.

Be clear and direct

Rather than being too polite by saying "Would you like to help me with this?", say "I'd like you to help me with this please".

Very open questions like "How's the job seeking going" can be hard to answer. Be more specific, and ask something like "Have you applied for any jobs this week?"

I may struggle to communicate in busy places

I may be overwhelmed by background noise, movement or even smells, and struggle to focus.

There's a danger I might agree to things I haven't fully understood just to get away from all the distractions.

Interacting with other people

I may struggle when put on the spot

For example, I might find unexpected phone calls difficult and struggle to work out what to say. Some autistic people find phone calls really challenging and prefer text or email.

Sarcasm and banter

I may struggle to work out if someone is just having fun, or whether they're being nasty.

I may need help to tell the difference, and work out whether a person is a real friend or someone who might pretend to be my friend to get something from me.

Small talk

I may not see the point of small talk, or perhaps just not be very good at it.

I may struggle to think what to say, worry about saying the wrong thing, and end up just staying quiet.



I may enjoy time on my own

I may not want to be as sociable as many other people are. I may prefer to have a small group of friends and family.

I may mask my autism at times

I may not want to come across as different, so might stop myself doing things like rocking, try to give eye contact, and laugh at jokes I don't really understand when with other people. Masking takes up a lot of energy as I have to think carefully about everything I say and do. I may get very tired after a lot of interaction.

Animals don't do sarcasm !

I may really enjoy spending time with animals, and if I have a pet we are likely to have a really strong bond. Dogs are very loyal and reliable. Animals don't lie, and they certainly don't confuse us with sarcasm !

Groups and friendships

I might find groups tricky at times, as it's hard to keep up with the conversation, and know when to speak.

I may struggle to work out how to make friends. It's like there's a secret code that I can't quite work out.

I may enjoy socialising but find it tiring



I may need breaks from socialising

I may find socialising really tiring, as I often have to work harder to work out what people are saying, and to keep up with conversations.

Busy places are particularly tiring, and I may need time to recover afterwards. Having short breaks during an event can help, and I may also prefer just to stay for an hour or two, rather than the whole evening.

I may need help to notice that I'm starting to feel tired and overwhelmed.

Quiet time together

I may enjoy being around other people without feeling pressure to interact with them.

I may focus more on the activity than the social aspect.

Socialising together around shared interests can be good, for example, online gaming with other people.

Helping me make sense of a sometimes confusing world

I may need help to understand the behaviour of other people

Sometimes people behave in really confusing and inconsistent ways, and this can cause me a lot of anxiety. I may tend to think that it's my fault if someone is in a bad mood, even if it's nothing to do with me.

Supporting me to try to work out other people's intentions helps. For example, I may not work out that the person being friendly wants to sell me something.



I may need help to see the big picture in situations

I may struggle at times to work out everything that's happening in a situation. You may be better than me at seeing the big picture.

For example, my manager asked me if I had said something on Twitter about the company. I was really upset as I thought he was accusing me. He later explained that he had asked everyone in private, which of course I hadn't known.

I might not pick up on some social rules

These can be really confusing - there should be a guide book to follow !

I may get very anxious about making social mistakes, such as asking people questions that are too personal, or turning up at a party too early (even when the invite says 7pm, apparently it doesn't mean 7pm !).

I might get stressed when people break the rules, such as walking on the grass when you're not allowed to.

I may not always be aware of how I come across to others

For example, I know that I'm not a threatening person, but if I'm wearing my headphones and have my hood up, other people may think I look a bit threatening.

I may need things to be correct

I may find it hard to settle if something is unfinished, or not quite right. For example, if a report written about me isn't accurate I might feel anxious and find it hard to let things go.

I may need support to stay safe



I might think other people are just as honest as me

I may find it hard to work out if people are being manipulative, or trying to take advantage of me.

I may have been bullied by others

This is very common for autistic people, particularly at school and college. The fear of being bullied is one of the things that can make new situations with unfamiliar people feel scary.

I may get overwhelmed if things don't go to plan, or there's a misunderstanding

I may get into misunderstandings with other people at times, and need help to sort the situation out. For example, I may get distressed in a shop if something happens like my card is declined. It's possible that at times I might do or say something that could be inappropriate, or be misinterpreted as inappropriate.

I may experience sensory things differently

Different autistic people have different sensory sensitivities

Many autistic people find noisy and busy environments overwhelming at times, and some people may also have differences with their visual, taste, touch and smell sense.

- Some people may find certain smells overpowering and impossible to be around.
- Some people may find certain textures, or unexpected touch very uncomfortable.
- Some people may not like certain food textures or flavours.
- Some people may find lights very bright, or busy walls overwhelming at times.



It's too simplistic to say that autistic people don't like noise

I may enjoy listening to loud music, but also find certain background noises unbearable, making it hard for me to focus on anything else.

I may not filter out background noise in the same way you can.

I may not fully understand my sensory differences

I may wonder why I seem to find certain situations more difficult to manage than other people do.

When feeling tired, anxious or unwell my sensory sensitivities may feel amplified.

I won't just get used to things

I may not get used to a noisy neighbour, road noise or even certain smells. These things are always likely to bother me.

My internal body senses may work a bit differently too

I may be very sensitive to pain, or even not always notice pain. Some autistic people may struggle to notice that they feel hungry or thirsty.

I may get nervous on escalators as my balance sense is a bit slower, and I may be more likely to get travel sick. I may find it hard to describe my symptoms when I'm not feeling well.

I may find lights too bright sometimes

I may also like to avoid visual clutter, and have quite plain walls at home.

Helping me manage my sensory differences



I may need to avoid really busy places

I might prefer to go shopping at quiet times. It may help me to use noise cancelling headphones or tinted glasses to help reduce the sensory input in busy places.

Support me in stressful situations

You might notice I'm overwhelmed before I do. You may be able to help me explain my symptoms at a health appointment. Things like a fidget toy or even a weighted vest may help me keep calm.

I may really enjoy sensory activities

I may like using things like a weighted blanket, and aromatherapy oils.

I may enjoy being out in the open air, and love the feel of the wind on my face.

My sensory differences can bring pleasure as well as discomfort.

I may find uncertainty really frightening

I may really like familiar things

I may not have the same need for variety as you. For example, I may like to order the same meal each time at a restaurant.

Things being consistent and predictable might be really important to me, as the world can seem very confusing a lot of the time.

When things change, they feel more uncertain

I may need more time to get used to the idea of change, particularly when it's unexpected or sudden. It can take me a long time to work out how I feel about a new plan, and I may simply say no at first out of fear. I may need to ask lots of questions to help me fully understand what's involved.

I may struggle to work out what to do with myself if the thing I had planned is cancelled. Uncertainty can make me feel unsafe.



New situations can feel very uncertain as well

I may need support when going to a new place, or doing a new activity for the first time. For example, going to a new leisure centre might involve an unfamiliar journey, a new system for signing in, a new building to find my way around and different lockers to work out. By the time I get to the gym or my class I'll probably already be exhausted !

Routines can help make things feel more predictable



I may rely on my routines for security

A familiar routine, such as following the usual route to work/college or a morning routine at home, puts less strain on my brain ! My routines may be really important to me, and I might plan things in a lot of detail. I may find it stressful if my usual routine is changed, or can't be completed. I'm more likely to use 'repetitive behaviours' such as rocking or doing tasks over and over when stressed.

I may find unstructured time difficult to manage sometimes

For example, at college I might find independent study time and lunch breaks challenging, as I'm not sure how to fill the time - what to do or where to go. I may need help to create structure and make a plan for these times.

I may find it hard to switch between tasks sometimes

I might be really engrossed in something and need to get it finished before moving onto something else. I'm likely to be better at doing one thing at a time than trying to multi-task.

Having things written down, or designed with pictures can be really helpful

These 'visual supports' help as I can check them to reassure myself - like you do with your diary or rota. Some autistic people benefit from very detailed routines and lists.

I may need support to organise myself



I may need support to set up my routines

I may get overwhelmed by everything I need to do, and struggle to know where to start, what are the most important things to do, and which order to do them in.

I may need help to set up systems and routines which I can then follow.

I might need help to break tasks down

I may get overwhelmed with large tasks and can't work out how to get started, even if I'm really motivated.

Breaking tasks down helps, so instead of planning to 'sort out the kitchen' I have a list to work through in order.

I'm likely to find it easier to learn visually - to be shown rather than told.

I may find certain tasks difficult, and find it hard to judge when things are good enough

For example, I may struggle to work out how to use a new washing machine because it's different to the one I'm familiar with, or I may struggle to judge when something is clean enough.

I want to do things for myself

I may get frustrated if people do things for me. Once tasks are broken down into steps it's easier, and it can help if I start by doing the last part by myself, then working backwards to do each previous step independently.

I might need help to keep track of time

I may find it hard to judge how long things will take. For example, I might need help to work out what time to leave to get somewhere on time.

I may use alarms to judge when food is cooked, rather than judging it by instinct.

Give me ideas

Suggest options rather than just asking me to tell you what help I need. I may struggle to imagine possible solutions to problems.

Apps might be helpful

There are apps that can help with things like organising schedules and different tasks.

I may need help to understand my emotions



I may struggle to recognise my own emotions

I may not always experience emotions straight away, so I may be confused about what has upset me. I may feel the emotions much later after the event. I might then feel these emotions very intensely.

Recognising other people's feelings

I may sometimes find it hard to recognise how others are feeling, and it helps when people support me with this. Often once I realise a person is upset I'm really caring and supportive.

I may need help to manage my emotions

I may get very upset or angry sometimes, and feel overwhelmed by my emotions. I may need support to help me calm myself down.

I may experience a lot of anxiety

I may struggle to switch off at times

Many autistic people describe having difficulties switching off. They feel they are 'on alert' most of the time and find it hard to relax. I may worry about details that other people don't see as important.

Anxiety is a separate thing to autism

People may assume I'm anxious because I'm autistic and there's nothing anyone can do.

I may need help to get treatment for my anxiety which can be treated as a separate condition.



Structure can really help me

I may rely much more on my calendar, lists and timetable when I'm anxious. They give me certainty, and help things to feel less chaotic and out of control.

Overthinking

When feeling anxious I may over think things and fear the worst.

Help me to think of all the other possible outcomes too, many of which might be more likely than the worst case scenario.

Noticing my anxiety

Help me to notice the signs that I'm anxious. For example I may start pacing around a lot.

Help me control the things I can

If something's making me anxious help me think about what actions I can take, and support me to do them. It also helps to suggest things I can distract myself with.

I may get overwhelmed at times

Help me avoid overwhelm as much as possible

It helps to have a back up plan in case things unexpectedly change. It helps to avoid places like a shopping centre at peak times.

I may need to stim

Doing repetitive things like rocking, flapping, repeating phrases or pacing can help me cope in overwhelming situations.

Help me find calming strategies that work for me

This could include escaping into my interests, using mindfulness, sensory strategies or even physical exercise. When feeling overwhelmed I may struggle to remember my strategies as I might not be able to think clearly. Having a list of strategies can be useful.



Support me if I have a meltdown or a shutdown

When extremely overwhelmed I may not be able to process any more information. My mind may just shutdown, or I may become very distressed or angry - known as a meltdown. I may need help to keep myself and others safe.

Ideally I will need a quiet place to recover and not have people crowding around me. It will take me time to recover, and it's important not to overload me any further by asking questions or offering choices.

It can really help to write a plan together about the best way to support me when I'm very overwhelmed, and make sure that everyone who supports me is aware of the plan, and what to do.

A few final thoughts



Don't try to make me 'less autistic'

I may behave a bit differently to you at times, and that's okay. For example, I may need to 'stim' to help keep me calm in a busy environment. If there's a danger my stimming may be harmful, help me to find an alternative.

Accept that I might have a different communication style. I'm likely to be already working hard to adapt to better fit in with non-autistic people, and working all these things out can be exhausting. It's important that I also have time and support just to be myself without having to think about everything I say and do.

Help me understand about myself and my autism

I may not understand autism very well, so it may help me to learn more about sensory differences, communication differences and my strengths. It may be helpful for me to get to know, and learn from, other autistic people who experience things in a similar way to me



My ideal life might not be a typical life

It's important that autistic people are encouraged to be themselves. An autistic person may need support to develop a lifestyle that suits their needs. It's okay not to enjoy all the things most other people do.

The Surrey Autism Partnership Board website

Our website lists services that are available to autistic adults, including people not eligible for adult social care support. For example:

- The National Autistic Society Assist service
- Employment support
- Diagnostic services

You will also find details about our reference group for autistic adults on our website, and minutes of our partnership board meetings.

www.surreypb.org.uk

Other information you might find helpful

Another handout in this series is aimed at social work teams, and goes into many of the issues described in this handout in more detail. It is illustrated with real life examples of people's experiences. Go to www.autismbyexperience.co.uk to find this handout.

