



**Autism  
seminars**  
for families

# Understanding autism

Seminar booklet



**Published in 2017 by The National Autistic Society**

**393 City Road, London EC1V 1NG**

**[www.autism.org.uk](http://www.autism.org.uk)**

All rights reserved. No part of this book can be reproduced, stored in a retrievable system or transmitted, in any form or by means electronic, mechanical, photocopying, recording or otherwise without the prior permission of the copyright owner.

**Copyright © The National Autistic Society 2017**

**ISBN 978-1-910707-06-7**

Illustrations by **Claire Lythgoe**



**With thanks to the Morrisons Foundation for their support.**



# Understanding autism

## Seminar booklet

This seminar booklet is designed to accompany the **Understanding autism** seminar.

A range of people deliver this seminar, including National Autistic Society employees and professionals who have bought our facilitator pack. The materials in the pack, including the presentation and seminar booklets, have all been written and developed by The National Autistic Society.

The seminars and booklets are based on the highly successful *help!* programme The National Autistic Society developed in 2002.

This seminar you are attending today is being delivered by:

### Language used to describe autism

Our most recent research into the language we use to describe autism showed there is no single term that everyone prefers. Although it does suggest a shift towards more positive and assertive language, particularly among autistic communities, we recognise that many parents prefer 'person-first' language such as 'child with autism' and 'child on the autism spectrum'. Therefore we have used these terms throughout this booklet.

For more information on the research, visit [www.autism.org.uk/describingautism](http://www.autism.org.uk/describingautism).

## Contents

The road to diagnosis	3	Sensory differences	13
What is autism?	5	Additional diagnoses	15
Social communication	7	Supporting communication	17
Social interaction	9	Sources of support	23
Restricted and repetitive patterns of behaviours, activities or interests	11	And finally...	25
		Useful reading	26

# The road to diagnosis

**This section describes the experiences of families who have received a diagnosis of autism (including Asperger syndrome) for their son or daughter, and some of the pressures that having autism in the family may bring about.**

## Length of diagnosis process

Diagnosis of autism can be a long and complex process for some families. It can either be carried out by an individual or a multi-disciplinary team. The whole process of getting a diagnosis for your child may affect your feelings towards, and understanding of, the diagnosis. Some parents say they received an excellent service from the person or team who diagnosed their child; others report a much more frustrating experience.

Parents who have had to battle to get a diagnosis may feel relief but also anger, while others may feel shocked if the diagnosis came as a complete surprise. The age at which diagnosis was made and the difficulty with which it was obtained is likely to have an effect on how you feel.

A diagnosis of autism is not always made before your child starts school and sometimes it doesn't happen until much later, even as late as adulthood. Therefore the route to diagnosis will often be a struggle and this in itself can be a cause of stress for family members. As one parent said, "the stress is not knowing".

## Different reactions to diagnosis

Your family will come to terms with the diagnosis of autism in its own way. There is no right or wrong way for you and other family members to react and cope with the news. The feelings that each parent, sibling and other family member has may vary.

Some parents say that they came to terms with it quite easily and now 'just get on with it'. Other families report that their feelings waver between positive and negative depending on what sort of day they have had with their child.

Some people have likened parental reactions to having a child with a disability as similar to the feelings described in situations of loss – a feeling of shock, then denial, anger, grief and finally acceptance. For some parents, part of the process of coming to terms with their child's disability involves feelings of loss for the child they thought they had. Although not all parents share these feelings, they can be a useful illustration of the wide-ranging emotions you may experience at different times.

It can take time to make sense of your child's diagnosis and accept the implications for family life. You may have to re-evaluate your hopes for your son or daughter's future, as well as your lifestyle, job, finances, holidays, family activities, even friends. One parent described the day they received their son's diagnosis as "the day our lives changed". Some studies have shown that having a child with a disability can put pressure on the parental relationship.

On the positive side, parents and families in other studies have claimed that having a son or daughter with autism has made them stronger and more capable people. One parent said, "You will meet people in your life now that you would never have met if you weren't setting out on this journey. You will meet the most kind, genuine, imaginative people, and if you weren't entering this world, you would never have had the opportunity to do that."

## Sibling reactions

If you have other children, explaining the diagnosis to them may be difficult. Each family will have its own way of approaching this but the more openly autism can be talked about, the easier it can be for the whole family to accept it and make the necessary adjustments. Your explanations can be quite short and simple. You can add knowledge over time, as circumstances dictate and situations arise. There are several good books written specifically for siblings, which are available at [www.autism.org.uk/shop](http://www.autism.org.uk/shop).

One of the most frequent difficulties families face is having to deal with sibling rivalry and fighting. Teaching all your children about autism and making house rules are often useful tactics for overcoming this, as is trying to make sure that all your children feel they are listened to and have their own needs recognised. Difficulties should be talked about and not ignored, as it is likely that family life seems 'unfair' at times for your other children.

It is important for siblings to feel they can voice their annoyance and fears openly. It is also important that they receive information about autism and that they do not feel overly responsible for their brother or sister.

As your other children get older, they may worry about the role they will have to play in their brother or sister's future. They may also worry about whether their own children will have autism. Both of these issues may require discussion with someone who is a knowledgeable and experienced professional, for example your GP, paediatrician, Child and Adolescent Mental Health Services (CAMHS) professional or social worker.



## Grandparent reactions

Some grandparents find a diagnosis of autism for their grandchild difficult to understand and accept, while others may find it easier. If your child displays some difficult behaviour at home, but not when they are with their grandparents, it can be hard for grandparents to understand these difficulties.

Grandparents may find it hard to play the typical 'grandparent role' with children on the autism spectrum. For example, it is typical for grandparents to be able to bend the rules with their grandchildren, but this can be confusing and upsetting for children with autism.

Parents attending autism seminars for families over the years have reported differing degrees of support from grandparents. This can range from a high degree of support right through to no support whatsoever. For some families, the wider family would like to offer support but this may be difficult for parents to take up because of their child's reactions to being with other people.

## Public reactions

Autism is still regarded as an 'invisible disability' because it is not always obvious that the person with autism has a disability. Although many people have heard of autism, few people really understand the condition. The behavioural signs can at times be quite hard to see and explain, so the general public may not appreciate that your son or daughter has any real problems with social situations. Taking your child out in public can, at times, be very stressful and tiring and can sometimes lead to quite embarrassing situations. Finding ways around this is important for the whole family.

Finding ways to cope with the lack of understanding about autism that still exists is not easy.

You may like to consider some of the following tactics.

- Some parents carry around a small supply of cards that explain what autism is for those with no prior knowledge. These business-sized cards are available to buy from The National Autistic Society in packs of 50. They give a brief explanation of autism and Asperger syndrome and are designed to help parents, carers and people with autism or Asperger syndrome to deal with public reaction.
- Autism alert cards are available to buy from The National Autistic Society and can be particularly useful if you have a child who either runs away or gets lost. Other organisations also produce similar cards – ask your seminar facilitator about these.



The above resources are available to buy at [www.autism.org.uk/shop](http://www.autism.org.uk/shop).

- Some parents have found it helpful to have a pre-prepared phrase that they can use in response to people who make comments about their child. This might involve finding a way to inform those people gently that their child has autism. Other parents feel that they do not want to tell the other person anything.

## Make a note

Your experience of the diagnostic process

---

---

---

---

---

---

---

---

---

---

# What is autism?

**Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.**

Autism is a 'spectrum disorder', meaning that the condition affects people in different ways across all abilities, strengths, difficulties and intelligence.

Autism affects your child's ability to understand other people; whether your child has no spoken language and very little eye contact, or whether they speak a lot and like to be around other people. But as well as their autism, your child will have their own genetic inheritance, personality, and life experiences that shape who they are.

## What causes autism?

Autism is thought to be the result of brain differences caused by genetic and other influences. The exact causes are not yet understood. It is generally accepted that children are born with autism, rather than develop it later, although in some children it may not be noticed early on as development varies. What we do know is that no one is to blame for autism and it is no one's fault. It just happens.

## How many people have autism?

Research has shown that more than 1 in 100 people have autism. People from all nationalities and cultural, religious and social backgrounds can have autism.

## Why do more boys than girls have autism?

Studies have shown that more boys are diagnosed with autism than girls. The general ratio of boys to girls is 4:1 for classic autism and 15:1 for Asperger syndrome. It is not yet understood why there is this difference. While boys are more likely to be diagnosed, studies vary widely in the ratio found, between 15:1 and 2:1.

Many experts have speculated that often girls with Asperger syndrome are not referred for diagnosis, and so are simply missing from statistics. This might be because the diagnostic criteria for autism, especially Asperger syndrome, are based on the behavioural characteristics of boys, who are often more noticeably 'different' or disruptive than girls with the same underlying traits.

Girls with Asperger syndrome may be better at masking their difficulties to fit in with their peers, and in general have more social skills.

## What does it feel like to have autism?

The quote below is just one person's experience, but many children and adults with autism will have times when it reflects how they feel:

"Reality to an autistic person is a confusing interacting mass of events, people, places, sounds and sights... A large part of my life is spent just trying to work out the pattern behind everything. Set routines, times and rituals all help to get order into an unbearably chaotic life."

Therese Jolliffe

## There are many different names for autism

The most common terms used are autism, Asperger syndrome or Autism Spectrum Disorder or Condition (ASD or ASC) but there are other terms that some professionals use to describe different forms of autism, including:

- high-functioning autism (HFA)
- childhood autism
- autistic disorder
- pervasive developmental disorder – not otherwise specified (PDD – NOS)
- semantic pragmatic disorder
- atypical autism
- Kanner's autism
- Kanner's syndrome
- classic autism.

## Pathological Demand Avoidance (PDA)

Pathological demand avoidance (PDA) is increasingly, but not universally, accepted as a behaviour profile that is seen in some individuals on the autism spectrum.

People with PDA share difficulties with others on the autism spectrum in the social aspects of interaction, communication and restricted and repetitive patterns of behaviours, activities or interests. However, those who present with this particular diagnostic profile are driven to avoid everyday demands and expectations to an extreme extent. This demand avoidant behaviour is rooted in an anxiety-based need to be in control.

While the PDA profile has been found to be relatively uncommon, it's important to recognise and understand the distinct behaviour profile as it has implications for the way a person is best supported.

### Features of the PDA profile

Autism is dimensional and the different profiles, including PDA, affect people in varying ways and to different degrees.

People with PDA seem to have better social understanding and communication skills than others on the spectrum and are often able to use this to their advantage. However, they might not really have as good an understanding of social matters as it initially appears.

- **resists and avoids the ordinary demands of life**
- **uses social strategies as part of avoidance, eg distracting, giving excuses**
- **appears sociable, but lacks depth in understanding**
- **excessive mood swings and impulsivity**
- **appears comfortable in role play and pretence**
- **language delay, often with good degree of catch-up**
- **displays obsessive behaviour, often focused on other people**

People with this profile can appear controlling and dominating, especially when they feel anxious. However, they can also be enigmatic and charming when they feel secure and in control. It's important to acknowledge that these people have a hidden disability.

People with PDA are likely to need a lot of support. The earlier the recognition of PDA, the sooner appropriate support can be put in place.

### What are the core areas of difficulty in autism?

For a diagnosis to be made, a person will usually be assessed as having had persistent difficulties with social communication and social interaction and restricted and repetitive patterns of behaviours, activities or interests since early childhood, to the extent that these limit and impair everyday functioning.

In addition to these core difficulties, autistic children and adults may also experience sensory processing differences. For some, these differences are significant and may require an additional diagnosis of Sensory Processing Disorder (SPD).





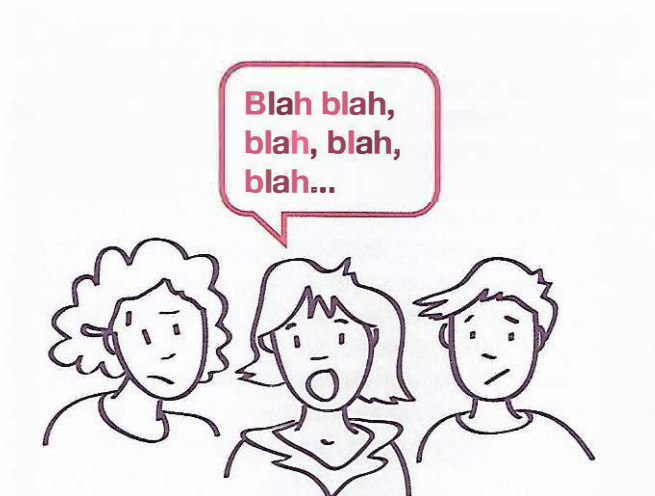
# Social communication

**Difficulties with social communication can include not knowing how to use words, facial expressions and gestures to communicate, or having problems with reading faces and understanding and using verbal and non-verbal communication.**

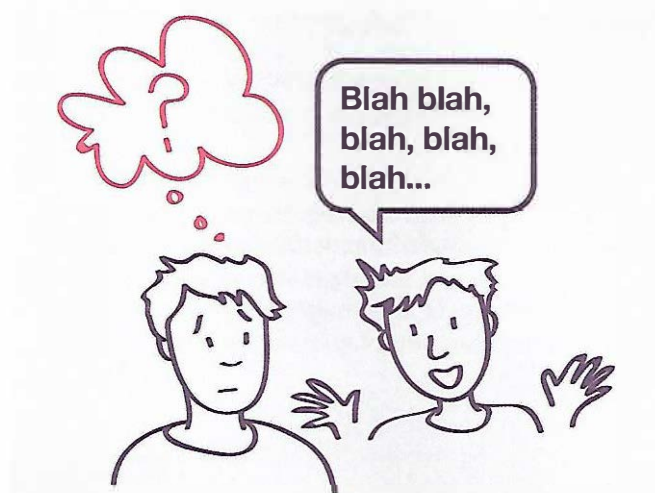
## **A child with autism:**

- may not appreciate the social uses and the pleasure of communication – this is even true of those who have a lot of speech, which they may use to talk at others and not with them
- may not understand that language is a tool for conveying information to others – they may be able to ask for their own needs to be met but find it hard to talk about feelings or thoughts and may not understand the emotions, ideas and beliefs of other people
- may not understand the meaning of gestures, facial expressions or tone of voice – more able children do use gestures but these tend to look odd and inappropriate
- may speak fluently but they may not take much notice of the reaction of people listening to them; they may talk on and on regardless of the listener's interest or seem to appear insensitive to their feelings
- despite having good language skills, they may sound over-precise or over-literal. Jokes can cause problems as can exaggerated language, metaphors and idioms; for example, a child with autism may be confused or frightened by a statement like “she bit my head off”.

Our goal is to develop the communication skills of children with autism so they can express their thoughts and feelings to others and build relationships.



May engage in isolated chatter unconnected to the conversation and often interrupt others when talking



May not understand other people's facial expressions and misinterpret non-verbal communication

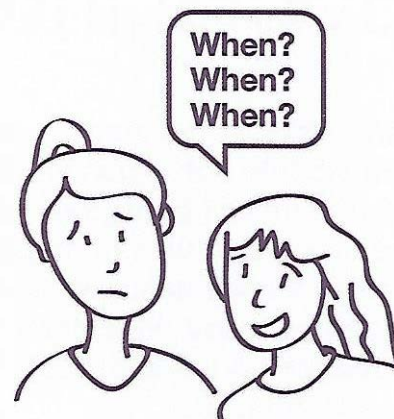




May engage in one-sided interaction and find it difficult to understand turn taking in conversation



May be able to name objects but has difficulty using words to communicate



May continually ask the same question even when answered

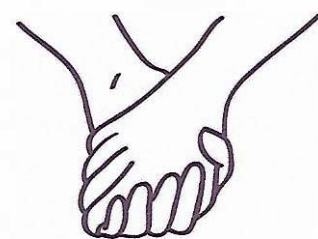
## Ways in which children on the autism spectrum might communicate



May not understand words or appear to only hear part of a sentence



May talk incessantly about one subject



May take someone's hand to lead them to what they want



May find eye contact difficult or painful



May repeat words/phrases spoken by others (known as 'Echolalia')

# Social interaction

**Difficulties in the area of social interaction can include not knowing how to behave around other people, not understanding the unwritten rules of behaviour and finding it hard to create relationships. Together, these difficulties make it hard for someone on the spectrum to establish and keep friendships.**

## **A child with autism:**

- may often appear aloof and indifferent to other people, especially other children, although some will enjoy certain forms of active physical contact
- may passively accept social contact and even show some signs of pleasure in this, but will rarely make spontaneous approaches
- may occasionally approach other people but in an odd, inappropriate and repetitive way, paying little or no attention to the responses of those they approach
- may try hard to be sociable, but still find it difficult to understand non-verbal signals, including facial expressions.

All children with autism need help in developing an interest in and understanding of social interaction.



May find it difficult to understand games and turn taking



Being with people can be quite stressful

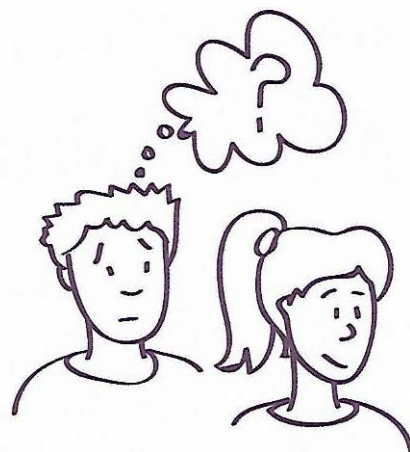




Won't look at others even when asked



Doesn't bring objects to others when requested



Never seems to listen and doesn't respond to their name

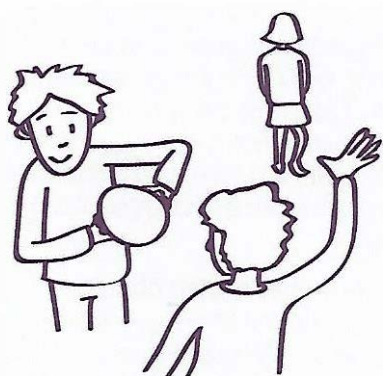
## Ways in which autism may affect social interaction



Refuses to let others join in or walks away



Unaware of social rules around personal space



Doesn't join in with games or activities



Allows an adult to join in but not a younger sibling



# Restricted and repetitive patterns of behaviours, activities or interests

**Difficulties in this area include inflexibility in thought and/or behaviour, a need for routines and finding it hard to imagine what may happen next (ie consequences of actions). Children may also have fascinations or obsessive behaviour based around certain objects or subjects.**

## **A child with autism:**

- may be unable to play imaginatively with objects or toys or with other children or adults
- may tend to focus on minor or trivial things around them, eg an earring rather than the person wearing it, or a wheel instead of the whole train
- may have a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively
- may miss the point of pursuits that involve words, such as social conversation, literature (especially fiction) and subtle verbal humour
- may find it hard to imagine what other people are thinking and feeling (this is sometimes described as poor theory of mind) so they can appear socially less skilled, naive and sometimes rude
- may have difficulty choosing between different options and imagining future events unless they can actually see them or experience them first hand
- may find it hard to think in abstract ways – this can cause problems for children in school where they may have difficulty with certain subjects, such as literature or religious studies.

We can help children with autism by providing structure and stability, while also gradually introducing changes so they can develop flexibility.



May have difficulty understanding the consequences of actions

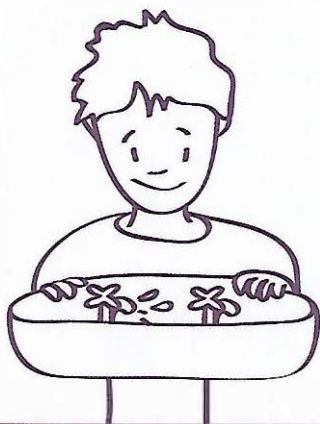


Change may be difficult and could cause upset

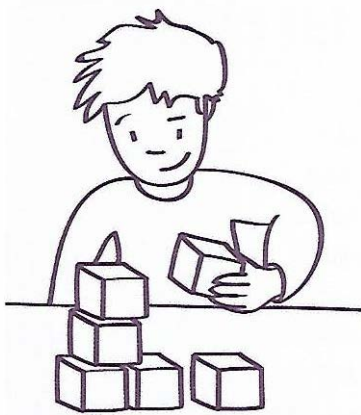
## Repetitive activities

### **A child with autism:**

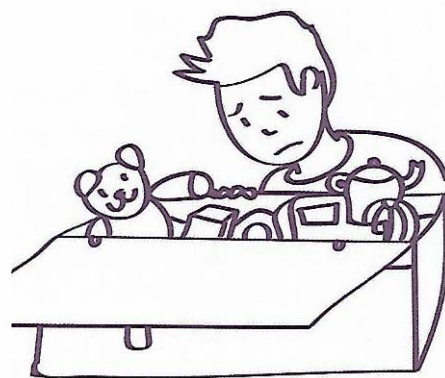
- may often show repetitive activity or behaviour. At a simple level this might involve repeatedly flicking their fingers or an object like a piece of string. More complex signs might include insisting on following an identical route to certain places, a long bedtime ritual or repeating a sequence of odd bodily movements. This behaviour may be associated with anxiety.
- may form an intense attachment to particular objects for no apparent purpose, arrange objects in lines or patterns, or collect things like pebbles or plastic bottles. They may become fascinated by certain topics, such as electricity, astronomy, birds or train timetables, or even specific people, asking the same series of questions and demanding standard answers.
- may be upset by any unexpected change in routine. Some children may impose their own routines, such as insisting on always walking the same route to school.



May have fascinations or engage in obsessive behaviours around objects/ subjects

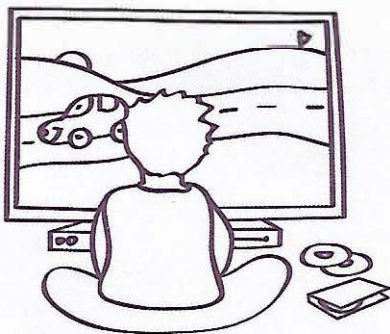


May engage in repetitive play or activities

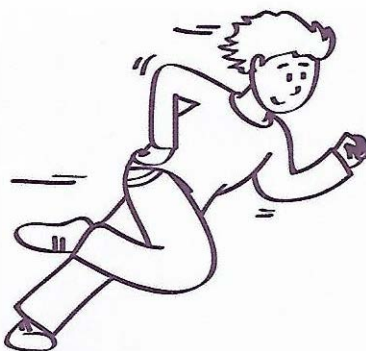


May have difficulty with imaginative play

## Ways in which restricted and repetitive patterns of behaviour may be displayed



May watch the same DVD over and over again



May run off – lack of awareness of danger



May have difficulty picking up on how others are feeling



May have a need for sameness with everything in its place



May have difficulty imagining what might happen next



# Sensory differences

What we see, hear, feel, smell and taste gives us information about our environment and ourselves. It helps us make sense of the world and enables us to act appropriately within it. It seems that many autistic people have sensory experiences that are heightened or reduced, causing them to perceive the world differently.

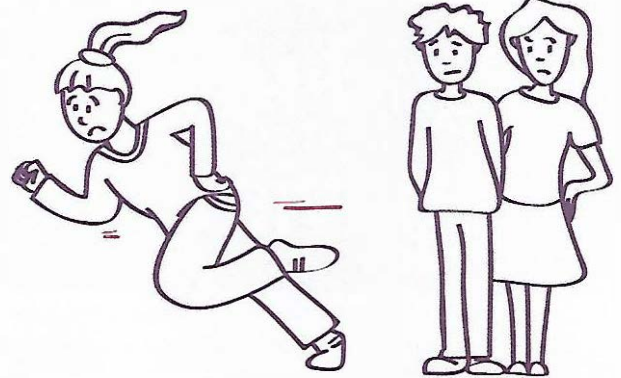
Although sensory differences on their own do not give rise to the diagnosis of autism, it is worth bearing in mind that the way your child experiences the world may be very different to the way someone without autism experiences it.



May make quite a lot of noise but be upset by loud sounds

Listed below are the seven sensory systems and their functions.

- **Touch (tactile)** – provides information about the environment and object qualities and textures, such as whether they are hard, soft, sharp, dull, hot, cold or painful to the touch
- **Sight (visual)** – provides information and helps to define boundaries as you move through time and space
- **Hearing (auditory)** – provides information about whether sounds in the environment are loud, soft, high, low, near or far
- **Smell (olfactory)** – provides information about different types of smell, such as musty, acrid, putrid, flowery, pungent
- **Taste (gustatory)** – provides information about different types of taste, such as sweet, sour, bitter, salty, spicy
- **Balance (vestibular)** – provides information about where your body is in space and whether you or your surroundings are moving; tells you about the speed and direction of movement
- **Body awareness (proprioception)** – provides information about where a certain body part is and how it is moving.



May avoid over-stimulating situations





May dislike being touched or held



May have sensitive vision or difficulty judging depth or tracking movement



Poor balance may affect ability at sports

## Ways in which sensory differences may affect your child



Diet may be a problem



May show an unusual reaction to pain



May hand flap, rock or spin



May find it difficult to coordinate their body position when walking or sitting

# Additional diagnoses common in children with autism

**Some children may experience other difficulties as well as having autism. The following are some of the more common diagnoses.**

**Dyspraxia** is a lifelong condition affecting fine and/or gross motor coordination in children and adults. Children may present with difficulties with self-care, writing, typing, riding a bike and play as well as other educational and recreational activities.

**Dyslexia** is a specific learning difficulty that primarily affects the ability to learn to read and spell. It often runs in families and stems from a difficulty in processing the sounds in words. Ten per cent of the UK population are affected.

**Attention Deficit/Hyperactivity Disorder (ADHD)** is the term used to describe children who have great difficulty with impulse control, maintaining attention and who are hyperactive.

**Tics** are physical mannerisms that are hard or impossible to control such as throat clearing, saying certain repetitive vocal phrases or making repetitive body movements.

**Anxiety** is common in many children who have autism. This is not usually diagnosed separately, unless it is severe.

**Depression** is sometimes diagnosed in young people on the autism spectrum.

**Learning disability** (or learning difficulties) is present in some children who have autism. This means they score below about 70 (on average) in IQ tests. Children with autism can have different 'degrees' of learning disability, which can affect all aspects of their life, from studying in school to learning how to wash themselves or make a meal.

**Epilepsy** is a condition in which the affected person has seizures or periods of loss of consciousness. It is sometimes present and seems more common in children who have autism and a learning disability.

## Some common strengths in children with autism

Although children with autism face quite a few difficulties in life, they can contribute a lot to the world around them. They have a number of skills and strengths which may include:

- **attention to detail**
- **good memory and concentration if of interest**
- **fascination in area of interest**
- **honesty is the best policy...**
- **abides by the rules – if understood**
- **fewer social inhibitions**
- **different way of seeing the world.**

It is important to focus on these qualities as well as supporting your child's development in areas where they are less able. It is worth knowing there are plenty of autistic adults who do not see the diagnosis as a lesser way of being, more as a difference.

“Living and working with people with autism spectrum disorders is not like living and working with anyone else, with or without disabilities. Past experiences of social interaction and a desire to help are not sufficient guides. It is essential to understand the nature of autistic conditions. People with these disorders, because of their social impairments, cannot meet you halfway. You have to make an imaginative leap into their world and try to see things from their point of view.”

Lorna Wing, 1995

## Make a note

Note any similarities or differences with your child and the film

***Amazing things happen***





# Supporting communication

**Autistic people have difficulties in how they communicate and interact – but the range of differences is vast because every child with the condition is different.**

Communication is a two-way process. It is about sending a message from one person to another (or to many others). This message could be about getting your needs met or sharing ideas, thoughts or feelings. We all do this through a variety of ways using words, sounds, tone of voice, expressions, eye contact and body language.

Some children with autism develop spoken language by the time they have started school, others don't. Others have a wide vocabulary but don't always understand how to talk in a way that will develop relationships.

The most important thing for any child to develop is a way of communicating, and it is equally important for parents to find the best way to communicate with them. This communication often involves words, but not always. Some children use alternative ways to communicate that work effectively for them, eg pointing, gesturing, and visual symbols. Sometimes a system can be used to help children understand the purpose of communication, eg the Picture Exchange Communication System ([www.pecs.com](http://www.pecs.com)).

It is important to try to see the world from the point of view of the child and adapt how we express ourselves, as well as help the child with autism learn social ways to communicate.

Communication and interaction skills can develop throughout your child's life, given the correct support. This section will give you ideas to try with your child, whether they are younger or older, and whether or not they use spoken language.

## Say his or her name first

For many children with autism, getting them to move their attention away from what they are already doing and on to another person is very difficult. Some children, unless we use their name first, will not realise that we are talking to them (even if they are the only other person in the room).

It is also important to note that if you say "children" or a teacher says "class 3", your child may not realise that this also includes them.

Other important things to think about when trying to get your child's attention are being in the same room and at the same level.

## Allow more time for processing

This is often referred to as '*the six second rule*' (or the eight, ten or twenty second rule!).

Children with autism often find processing verbal language very difficult and it can take them much longer than other children, especially during times of high anxiety.

After saying something to your child, allow time for him or her to process what you have just said before you go on to the next piece of information. The time you allow can be counted in your head. For many people, counting about six seconds is a good rule of thumb, but be prepared to experiment with this. Some people will need about six seconds, some a bit longer and a few less time.

Luke Jackson, an autistic adult talking about his experiences of growing up says, "We clash because Mum is too fast for me... Mum will shout 'Luke put your Taekwondo uniform on' and by the time I've processed the information she's shouting in my ear again." (Molloy and Vasil, 2004, p. 98).

If you do need to repeat your instruction or information it is important you use the same words again in the same order, rather than altering what you have said. Waiting six seconds before repeating your instruction will allow your child time to process the information or request.

Remember this is not about a lack of understanding or intelligence, it is about needing slightly longer to process meaning from words.

## Be clear and specific

Although very short instructions may seem quite abrupt, most autistic people tell us that they prefer simple, clear communication. They may find it difficult to process or remember more than one instruction at a time.

For younger children, or those with limited understanding of language, it is sometimes a good idea to give instructions in the order in which they are going to happen, eg "John... shoes on... then coat on... wait at front door" may be better than "we're going in the car and I need you to put your coat and shoes on, then wait at the front door."

## Use fewer words and simple language

Children with autism process spoken words more slowly, so it is important to use fewer words and simple language. If you use too many words, your child may either not understand them or become overwhelmed.

If your child doesn't understand many words, the fewer you use, the easier it will be for them to learn what they mean.

If your child uses a lot of language themselves, they can still become overwhelmed if you use the same amount of language when communicating with them.

## Give available choices

It is important to let children know what the available choices are when offering them a choice. Start by only offering two choices, then as your child's understanding develops, you can start increasing the number of choices.

If you ask a child with autism an open-ended question, they may struggle to understand what is an appropriate answer. For example, if you ask "what do you want for dinner?", the child may be either unable to answer or answer with something that is unachievable, for example "16 McDonald's hamburgers please!"

## Use 'finished' rather than 'no' or 'stop'

Unlike the word 'no', the word 'finished' can be both positive and negative. You can use it both to signal the end of a meal or a piece of homework, or to signal that a negative behaviour needs to be stopped or it is time to stop doing their obsessive or special interest. By using the word consistently, you increase the chance of your child understanding its meaning but not dwelling on its negativity.

## Eye contact: look as if you are listening

Many children with autism can find eye contact very difficult. It can be uncomfortable, they may not realise they should do it or just don't pick up any information from it.

It is important to remember that encouraging eye contact can cause added stress for some children.

It may be useful to try to teach some children to at least look in another person's direction when they are talking to them. Many children say they look at a person's nose so it gives the impression that they are looking at them.

Some children with autism find it difficult to pay attention to more than one sensory input at a time, eg they might not be able to look and listen at the same time.

## Be aware of voice pitch and level

Children with autism will vary in how they react to change in voice pitch and level. Some may not notice at all, others may think you are saying something completely different (even if you said the same sentence louder) and others may misinterpret your intentions (eg you just said something a little louder but they think you are very angry with them).

If children process sensory information differently, this may also change how they interpret what other people say to them.

## Use positive language: 'do' vs. 'don't'

It is important to tell children with autism what they can do and let them know when they are getting things right. It is a more positive way of managing your child's behaviour and it can be helpful in trying to build their self-esteem by praising them for doing things right (eg "walk slowly in the hall" is better than "don't run" and "good walking" to give praise).

Many autistic adults and older children say that they wish their parents had actually told them when they were being 'social', 'polite' or 'friendly', so they would know what to do for next time.

It's worth noting that some children will need praise to be given in a happy but fairly neutral way rather than with lots of fuss, and some children don't seem to be bothered with other people's praise. Phrases such as "good talking" and "good turn taking" may be useful in supporting this.

## Using visual supports

As many children with autism find verbal communication difficult to understand, using visual methods to back up what you are saying can help them to understand better and are often less confrontational.

We all use visual supports to help us to organise our life, make choices, communicate with others and complete tasks.

For many autistic people, they are a vital tool – even if they have verbal skills.



## Provide structure to their day

Children with autism benefit from having predictability in their lives. This is often known as providing structure. Structure does not mean doing the same thing every single day, it means the child is in an environment where he or she feels safe and knows what is happening. Providing structure does not mean using the same routines forever, it means that changes are planned for and introduced carefully.

**Providing structure can be broken down in a number of questions. Does your child know:**

- what to do?
- how to do it?
- how long each activity lasts?
- what happens next?

This is one of the golden rules used in National Autistic Society services and schools. If someone with autism knows the answer to all these questions, they are more likely to feel secure in their surroundings.

## Do they know what to do (and in what order)?

It is very helpful for your child to know what he or she will be doing each day and during each part of the week.

As well as knowing what to do and what happens next, many children will benefit from having clear visual information about the order of daily tasks. It allows them to become more independent and also reduces their anxiety about what will happen next.

There are lots of ways to provide this visual information using schedules, calendars, timetables or keyrings with cards showing what activity happens next.

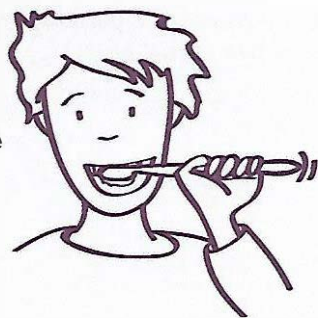
Using a picture strip to illustrate this, like the example, can help to reinforce the message.



## Do they know how to do it? (step by step)

As well as knowing in what order events and activities will happen, it is important for your child to know how to do daily tasks. You may need to break tasks down into each separate action for your child to understand and successfully accomplish the task.

- get toothbrush
- squeeze on toothpaste
- brush teeth for three minutes
- rinse toothbrush
- put toothbrush in holder.



## Do they know how long each activity lasts?

As well as knowing what order events will happen in, your child often needs to know how long an activity lasts and have warning of when it will finish.

Try to have a clear start and finish time and a clear warning of the ending. Using visual timers such as the ones below may be helpful.



Name of product: **Time Timer or Time Timer App** Where to buy: [www.taskmasteronline.co.uk](http://www.taskmasteronline.co.uk); National Autistic Society Amazon affiliate site: [www.autism.org.uk/shop](http://www.autism.org.uk/shop); or iTunes

Name of product: **Time Tracker** Where to buy: [www.amazon.co.uk](http://www.amazon.co.uk)

Name of product: **Sandtimer** Where to buy: [www.sensetoys.com](http://www.sensetoys.com)



Some parents find that using a countdown method works well. This lets their child have a clear warning that the end of an activity is approaching. It is often better to count down and finish on 5-4-3-2-1 rather than count up.

**‘Traffic light’** systems can work well for some. This involves making green, amber and red cards to place near your child (or just hold, for him or her to see) when they are doing an activity. Show the green card to your child while an activity is taking place, the amber card when the activity is coming towards the end, and the red card when it is finished, as well as telling him or her how much time is left.

Many parents find that using a ‘finish’ signal (eg a cross on a piece of card or sign with their hands) can be useful to make it clear when an activity has ended. Often this is backed up by saying “TV is finished”.

## More ‘chill out’ time

After school (and at other times) your child may need a bit of space. School is often stressful, and even for a child who enjoys it, the school day can be tiring.

Often a child who appears calm or settled in school may ‘explode’ once he or she gets home. Some children want to talk, but many others just need time alone to recover.

So you may want to consider giving them more space to ‘calm down’ or release energy, depending on what sort of day they have had. Examples include going on the trampoline, having a relaxing bath, or spending time alone away from brothers or sisters.

Some children will benefit from a timetable or set routine like the example below.

## Do they know what happens next?

Many children are helped by knowing what is happening next, particularly if this is what they see as a motivator. If we consistently use the words ‘first’ and ‘then’ along with the symbols or pictures, it provides the child with the consistent message that something will come next.



## Example timetable



## Prepare for change and transitions

For children with autism, variety is not always the spice of life. Life can be very confusing for them, causing anxiety and/or aggression, so they will often try to impose some predictability on their lives.

Routines will therefore be important to your child, but it is equally important that you gradually introduce variety into their life so they get used to unexpected changes. We need to introduce changes in such a way that they do not feel they have lost control or that their world has become too unpredictable.

### The order for introducing change should be as follows.

- 1 Make life as predictable as your child needs it to be so they are not in a state of constant stress or anxiety.
- 2 Once your child does seem more settled, gradually introduce small manageable changes to their routine.

Using a 'something different' symbol or card is one way to introduce unexpected changes to your son or daughter's routines.

If your child uses a strip with daily events on it, like the one below, then a different coloured background can be used to signal clearly that a change is taking place. Onto this 'something different' background you can attach whichever new activity is taking place.

If you try a system like the one just described, make sure that for the first several times you introduce the 'something different' card, you have a fun activity to offer. This way your child will be less scared of change and realise that it can be a good thing as it can bring pleasant surprises.

Obviously, sometimes in life we have to face less enjoyable changes to plans, but save this lesson for when your child has already accepted the 'something different' idea.

Prepare for new events in small steps. For example, if you want to take your child to an out-of-school club you may first need to take them to look through the window or stand at the door holding their hand, and then stay for five minutes. Alternatively, you could take photos of the new place and show them to your child before you go there.

Another common technique is to create a visual sequence that shows the main activity (eg go to the cinema) on the schedule but with a smaller picture or word underneath describing an alternative possible activity (eg play football if film is sold out). By letting your child know of this possibility from the outset, you may avoid an upset if the alternative becomes necessary, because it was always part of their schedule for the day.

To help children cope when events are impossible for anyone to predict, some parents have developed a 'question mark' or 'another plan' card to explain that nobody knows what will happen.





## Make a note

Which of these strategies do you use already?

Which of these strategies might you be able to use in future?



# Sources of support

**Parents and carers of children and adults with autism may be entitled to access services and financial help towards their care and support. However, getting support for someone with autism is often far from straightforward. As many parents already know, this can cause immense frustration and stress.**

Your seminar facilitator should be able to provide you with handouts detailing specific help that is relevant to your local area.

## The National Autistic Society

We are the UK's leading autism charity. Since we began over 50 years ago, we have been pioneering new ways to support people and understand autism. We continue to learn every day from the children and adults we support in our schools and care services. Based on our experience, and with support from our members, donors and volunteers, we provide life-changing information and advice to millions of autistic people, their families and friends. And we support professionals, politicians and the public to understand autism better so that more autistic people of all ages can be understood, supported and appreciated for who they are. Until everyone understands.

## National Autistic Society website

[www.autism.org.uk](http://www.autism.org.uk)

The website has a wealth of information on it, sections dedicated to individuals with autism, parents, grandparents, siblings, partners and professionals. It includes information sheets on a variety of different topics. It has specific areas for each country within the UK, for people who live overseas at [www.autism.org.uk/roundtheworld](http://www.autism.org.uk/roundtheworld).

## Autism Services Directory

[www.autism.org.uk/directory](http://www.autism.org.uk/directory)

The UK's most comprehensive directory of services and support for people with an autism spectrum disorder, their families, and people who work with them. It also contains a list of services overseas.

## National Autistic Society Helplines (UK)

We run a variety of telephone helplines that can offer impartial, confidential information, advice and support for people with autism spectrum disorders and their families and carers. All 0808 numbers are free from landlines and most mobiles.

### Make a note

Any useful support ideas from the seminar...

---

---

---

---

---

---

---

---

Any strategies you might be able to use in the future...

---

---

---

---

---

---

---

---

## Autism Helpline

0808 800 4104

Lines are open daily Monday to Friday.  
Check The National Autistic Society website for specific times. There is also an email service:  
[autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk)

The Autism Helpline offers a telephone interpretation service to callers from the UK whose first language is not English.

## Education Rights Service

0808 800 4102

Provides accurate information, support and advice on educational provision and entitlements to help guide parents through education law and what can often be a complex and difficult process. The service is provided by trained volunteers who offer telephone-based advice from their own homes.

## Parent to Parent Service

0808 800 4106

A confidential telephone support service, provided by trained parent volunteers, for parents and carers of an adult or child on the autism spectrum.

## National Autistic Society Helplines (outside the UK)

Our Autism Helpline may be able to provide you with contact details for a support service in your own country.

Email your enquiry to: [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk) or use the helpline enquiry form on The National Autistic Society website: [www.autism.org.uk/enquiry](http://www.autism.org.uk/enquiry).

## National Autistic Society Community

[www.autism.org.uk/community](http://www.autism.org.uk/community)

This is an online community for autistic people, their carers and relatives, professionals working around autism and other interested people to share their thoughts and experiences.

## Local support

There may be a range of support services you can access in your local area.

### Branches

We have more than 115 volunteer-led branches and groups across the UK, which cover almost three quarters of the country. Our hard-working volunteers take part in fundraising and campaigning activities, and run family support and information services to help people with autism in the local area.

Find your local branch at:  
[www.autism.org.uk/branches](http://www.autism.org.uk/branches).

### Local support or carers' groups

Many areas have a variety of local parent groups that you will be able to join. Some will be autism-specific, others may be more generic. Groups like this often run meetings that parents can attend, and some may offer more detailed information and advice.

### Local professionals

There may be teams or individuals from your local area that can provide support for you and your child. This can include professionals from education, health or other statutory agencies.

For more information about support in your area or country look at the local offer on your local authority website.

## National support

There may be a variety of national support services that that you can access.

### Advice or support organisations

There may be organisations that can give you advice or support on a variety of subjects. These may include advice on education, discrimination, getting financial help and general carer support. For more information about national support in your area or country please see the 'National support' handout.

### Additional entitlements

There may be specific support or welfare benefits that you can access in your area or country.

For more information about additional entitlements in your area or country please see the 'Additional entitlements' handout.

# And finally...

**The 'Understanding autism' seminar is a good introduction to understanding more about autism. There may be other seminars that you can attend that are either run by your local autism professional, by The National Autistic Society, or by other organisations, that will help you to keep increasing your own knowledge and understanding of autism.**

We are learning more about autism all the time, so it's important that we all remain open-minded about what the future holds.

Some important messages to take away that have come from parents who have attended The National Autistic Society family seminars:

## **Take care of yourself**

It is important to take care of yourself as well as your child. When you have a child with autism, you can find that they place a lot of demands on your time. Making sure you try and look after yourself will enable you to continue supporting them.

## **One step at a time**

There is often pressure on parents to try and do everything at once. But particularly when supporting children with autism, it may be better in the long run to take things one step at a time, not rushing yourself or your child.

## **Do what you can – when you feel ready**

It is important to do things when the time is right for you and your child.

## **Keep realistic expectations**

This should be both for your child and for yourself. Many families have said that once they reduced the pressure on themselves and their child, they felt a lot better.

## **Make time for yourself – 'chill out' even if only briefly**

This goes back to the importance of looking after yourself. We often talk about the importance of 'chill out' time for children, but it can be just as important for parents.

## **Make a note**

Next steps...



# Useful reading

Dickinson, P., Hannah, L. (2014). *It can get better – dealing with common behaviour problems in young autistic children*. London: The National Autistic Society

Ives, M., Munro, N. (2001). *Caring for a child with autism*. London: Jessica Kingsley Publishers

Attwood, T. (1998). *Asperger syndrome: A guide for parents and professionals*. London: Jessica Kingsley Publishers

Lawrence, C. (2013). *Finding Asperger syndrome in the family - a book of answers*. Brighton: Straightforward Publishing

May, F. (2005). *Understanding behaviour*. London: The National Autistic Society

Whitaker, P. (2002). *Challenging behaviour and autism*. Kansas: Autism Asperger Publishing Company

Smith Myles, B. et al (2001). *Asperger syndrome and sensory issues*. Kansas: Autism Asperger Publishing Company

Yack, E., Aquilla, P., Sutton, S. (2003). *Building bridges through sensory integration*. Las Vegas: Sensory Resources

Savner, J., Smith Myles, B. (2000). *Making visual supports work in the home and Community*. Kansas: Autism Asperger Publishing Company

Gray, C. (2001). *My social stories book*. London: Jessica Kingsley Publishers

Vermeulen, P. (2008). *I am special*. London: Jessica Kingsley Publishers

Welton, J. (2014). *Can I tell you about autism?* London: Jessica Kingsley Publishers

Welton, J. (2003). *Can I tell you about Asperger syndrome?* London: Jessica Kingsley Publishers

Fidler, R. (2015). *Can I tell you about pathological demand avoidance syndrome?* London: Jessica Kingsley Publishers

Attwood, T. (2014). *Been there, done that, TRY THIS!* London: Jessica Kingsley Publishers

Hendrickx, S. (2015). *Women and girls with autism spectrum disorder: understanding life experiences from early childhood to old age*. London: Jessica Kingsley Publishers

Hattersley, C. (2014). *Autism: supporting your teenager*. London: The National Autistic Society

Baron-Cohen, S. (2008). *Autism: the facts*. Oxford: OUP

Pike, R. (2016). *Autism: talking about a diagnosis*. London: The National Autistic Society

## Useful books for children with autism and/or siblings

Dura-Vila, G., Levi, T. (2013). *My autism book – a child's guide to their autism spectrum diagnosis*. London: Jessica Kingsley Publishers

Ives, M. (2002). *What is Asperger syndrome and how will it affect me?* Kansas: Autism Asperger Publishing Company

Cook O'Toole, J. (2012). *The Asperkid's (secret) book of social rules: The handbook of not-so-obvious social guidelines for sisterhood of the spectrum: an Asperger chick's guide to life*. London: Jessica Kingsley Publishers

Rowe, A. (2013). *Asperger's syndrome in 13-16 year olds*. London: Lonely Mind Books

Gorrod, L. (2000). *My brother is different*. London: The National Autistic Society

Hunter, T. (2006). *My sister is different*. London: The National Autistic Society

Doherty, K., McNally, P., Sherrard, E. (2000). *I have autism... What's that?* London: The National Autistic Society

Ives, M. (2002). *What is Asperger syndrome and how will it affect me?* Kansas: Autism Asperger Publishing Company

Barton, M. (2011). *It's raining cats and dogs: an autism spectrum guide to the confusing world of idioms, metaphors and everyday expressions*. London: Jessica Kingsley Publishers

Murray, D. (2005). *Coming out Asperger: diagnosis, disclosure and self-confidence*. London: Jessica Kingsley Publishers

Bleach, F. (2015). *Everybody is different - A book for young people who have brothers and sisters with autism*. Kansas: Autism Asperger Publishing Company

Brock, C. (2010). *I'm a teenager, get me out of here*. London: The National Autistic Society

Elder, J. (2005). *Different like me: my book of autism heroes*. London: Jessica Kingsley Publishers

Hoopman, K. (2000). *Blue bottle mystery: an Asperger adventure*. London: Jessica Kingsley Publishers

**Many titles are available to buy from  
The National Autistic Society online shop –  
[www.autism.org.uk/shop](http://www.autism.org.uk/shop)**

## Make a note



## Autism seminars for families

### The National Autistic Society

We are the UK's leading autism charity. Since we began over 50 years ago, we have been pioneering new ways to support people and understand autism. We continue to learn every day from the children and adults we support in our schools and care services.

Based on our experience, and with support from our members, donors and volunteers, we provide life-changing information and advice to millions of autistic people, their families and friends. And we support professionals, politicians and the public to understand autism better so that more autistic people of all ages can be understood, supported and appreciated for who they are.

**Until everyone understands.**

The National Autistic Society  
393 City Road  
London  
EC1V 1NG

Autism Helpline: 0808 800 4104  
Supporter care: 0808 800 1050  
Email: [nas@nas.org.uk](mailto:nas@nas.org.uk)  
Website: [www.autism.org.uk](http://www.autism.org.uk)

