Autism and asperger's: for parents, carers and anyone working with young people

This webpage gives details about Autism and Autism Spectrum Disorders, as well as offering practical advice about how to get help.

Disclaimer

This is information, not advice. Please read our disclaimer.

What are Autism Spectrum Disorders?

Autism is the central condition in the group of difficulties known as Autism

Spectrum Disorders (ASD) or Autism Spectrum Conditions (ASC). For simplicity, we will use the term ASD. They are **neurodevelopmental** disorders – which means they are caused by abnormalities in the way the brain develops and works.

They affect approximately 1 in 100 children and young people.

Children and young people with ASD have particular difficulties:

in communicating

being around people socially and with their

behaviour

They have a range of intellectual ability from having severe learning disabilities, to being more academically able and in mainstream education. About 10% of people with autism may also have some special skills and abilities.

For a diagnosis of autism, there must be evidence of unusual development in the first 3 years of life. Asperger's syndrome is a term used for some higher functioning people on the autism spectrum who have intellectual ability in the average range and no delays in learning to talk. Many often have intense interests such as train timetables, buses or dinosaurs.

What are the causes of Autism Spectrum Disorders?

The exact cause of ASD is still unknown, although research shows that a combination of genetic and environmental factors may account for changes in brain development. There is an increased risk of ASD and other developmental difficulties in the brothers and sisters of children with ASD.

<u>What are the characteristics of Autism Spectrum</u> <u>Disorders?</u>

The characteristics of children and young people with ASD will vary depending upon their age, developmental level and how severely they are affected.

The difficulties are also likely to change over time. Parents are usually (but not always) the first to have some concerns about their child's development, and difficulties may be noticed from as early as infancy. Overall, the problems and

behaviours can be divided into three main areas:

Difficulties with communication

Children and young people with ASD have difficulties with both verbal communication (speaking) and non-verbal communication (eye contact, expressions and gestures). Some children may not be able to talk at all or have very limited speech.

Some have good speech and language skills, but still have difficulty using their speech socially or to sustain a conversation. Their use of language may be overly formal or 'adult-like'. They may talk at length about their own topics of interest, but find it hard to understand the back and forth nature of two-way conversations.

Difficulties with social interaction

Children and young people with ASD have difficulty understanding the 'social world', for example, they often have difficulty recognising and understanding their feelings and those of people around them. This in turn can make it difficult for them to make friends. They may prefer to spend time alone, or appear insensitive to others because of their difficulties understanding social rules and expectations.

Difficulties with behaviour, interests and activities

Children and young people with ASD often prefer familiar routines (e.g. taking the same route to school every day, putting their clothes on in a particular order), and tend to have difficulties dealing with change, which they find difficult and distressing.

They may also have unusual intense and specific interests, such as in electronic gadgets or lists of dates. They might use toys more like 'objects' to line up, for example. They may have unusual responses to particular experiences from their environment such as tastes, smells, sounds and textures. For example, they could be very sensitive to the sound of a hair dryer, or the feel of certain materials against their skin.

Some children show unusual repetitive movements such as hand or finger flapping or twisting, or complicated whole body movements.

Where can I get help?

If you are worried about your child's development, or their school or nursery has contacted you about their worries, the first step is to speak to your GP or health visitor who will advise you and make a referral if necessary to the local <u>Child</u> <u>Development Team or Child and Adolescent Mental Health Service</u> (CAMHS).

Making the correct diagnosis requires a detailed discussion about your child's early development, medical and psychological assessment, and a comprehensive assessment of your child's social and communication skills and intellectual abilities. Some of this will be done by watching your child in different settings e.g. school. There is no single test (eg blood test or brain scan) for ASD. However, several different tests may be carried out to exclude other conditions (e.g. hearing tests and blood tests).

Learning difficulties

Children with ASD can have general or specific learning disabilities which may range from mild to severe. They will have their own strengths and difficulties, both with their learning and their abilities, like all children.

What can be done to help?

There are no known cures for ASD, but children and families can be helped in many ways. Help includes:

being given information about the condition

managing behavioural difficulties

developing social communication and emotional skills

medication in some cases.

There are various approaches available to help with communication and learning, and for children with ASD, it is often better to intervene as early as possible.

Usually, there will be several people involved in the care of a child with ASD, such as a speech and language therapist, psychologist, occupational therapist and a medical doctor (paedicatrician or child psychiatrist). There might also be specialist courses on parenting, parent support groups, advice on how to help the wider family and more general advice about benefits, for example, from local child health services and independent organisations such as the **National Autistic Society**.

<u>What are the education needs of children with</u> <u>Autism Spectrum Disorders?</u>

Children and young people with ASD often need some special educational support.

This may be in a special school, or in a mainstream school with extra help to manage conflict and upset feelings, and to get on with other people, for example.

Unstructured situations, such as break and lunch-times, can be very difficult for some children with ASD, who may be vulnerable to bullying or exploitation, particularly in secondary schools.

The future

Most children and young people with ASD continue to experience similar difficulties throughout life, although generally they become less severe over time. Getting help as early as possible for children and young people with ASD can make a real difference.

Case study: Kester, aged 9

I like playing on my computer and playing role playing games. It is OK playing on the computer because I can find people who like the same things as me.

Most of the kids at school think I am weird when I talk to them about my games. My Mum worries that I want to stay in my room and not see other kids my age after school.

I prefer to be on my own – other kids wind me up and then I lose my temper.

My Mum says I have got Asperger's Syndrome. I don't really understand what this is but I don't care. I know it means I am different from other kids – that I find it difficult to get on with other kids.

My Mum doesn't always understand when I want to do things like not wanting to wear socks or shoes. I do wear them to school but I take them off as soon as I get home.

Further help

Social services can have a role to play in providing practical support and help for the young person and their family.

They can provide help in accessing local services and resources, such as respite care, and advice on disability allowances. Many families also value support from their local autism parent and carer support group.

Further reading

The Complete Guide to Asperger's Syndrome (2006). Tony Attwood. Jessica Kingsley Publishers: London.

Finding Out About Asperger's Syndrome, High-Functioning Autism and PDD. Author Gunilla Gerland. Jessica Kingsley Publishers: London

Parenting a child with Asperger Syndrome – 200 tips & strategies. B Boyd (Jessica Kingsley)

It can get better. Paul Dickinson & Liz Hannah

The ASD Workbook: Understanding your Autism Spectrum Disorder. Penny Kershaw.

Further support

<u>The National Autistic Society</u> champions the rights and interests of all people with autism and aim to provide individuals with autism and their families with help, support and services that they can access, trust and rely upon and which can make a positive difference to their lives.

<u>**Contact a Family</u>**. UK-wide charity providing advice, information and support to the parents of all disabled children. Free helpline 0808 808 3555.</u>

<u>Research Autism</u> is a UK charity dedicated to research into interventions in autism.

References and credits

Rutter M et al. (2008) 'Rutter's Child and Adolescent Psychiatry' (5th edn). Oxford: Blackwell

Scottish Intercollegiate Guidelines Network. <u>Autism Spectrum Disorders:</u> <u>booklet for Young People.</u>

Scottish Intercollegiate Guidelines Network. <u>Autism Spectrum Disorders:</u> <u>Guideline 98: Assessment, diagnosis and clinical interventions for</u> <u>children and young people with autism spectrum disorders</u>.

National Institute for Health & Clinical Excellence (NICE). <u>Autism: Recognition</u>, <u>Referral and Diagnosis. Clinical guideline 128</u>

Information for people with learning disability and their carers

The Royal College of Psychiatrists' Faculty of the Psychiatry of Learning Disability and the Leicestershire Partnership NHS Trust have produced accessible information for people with mental health problems and learning disabilities. All these materials have been written and tested with people with learning disabilities and their carers.

Credits

Revised by the Royal College of Psychiatrists' Child and Family Public Engagement Editorial Board (CAFPEB). This resource reflects the best possible evidence at the time of writing.

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About this information

This information reflects the best available evidence at the time of writing. Our mental health information for young people was written in 2017 and will be reviewed in 2020.

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