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## **AUTISTIC SPECTRUM DISORDERS including ASPERGER SYNDROME**

The 'autistic spectrum' (also known as 'pervasive developmental disorder') is the term used for a range of disorders affecting the development of social interaction, communication and imagination. This triad of impairments may be due to severe problems in making sense of experiences, especially the complicated, constantly changing social world. This results in a lack of imaginative understanding of other people's thoughts, feelings and needs and difficulty in acquiring the subtle, unspoken rules of social interaction. Instead of the usual wide range of social interests, those affected have a narrow, repetitive pattern of activities that absorb most or all of their attention.

There is great variation in the way the triad is manifested and attempts have been made to define subgroups. The best known of these are 'typical autism' and 'Asperger syndrome'. The former term is usually used for those who have no interest in social interaction, little or no language, and who tend to live in their own world of stereotyped activities. Asperger syndrome is usually used for those who are more able, who have better language development and who try to make social contacts but in naive and inappropriate ways. In clinical practice, all suggested subgroups, including Asperger syndrome and typical autism, overlap with each other and the boundaries are unclear. A small proportion of individuals with the triad have remarkably high levels of ability in one or two specific skills in contrast to their impairments in other areas - the so-called 'autistic savants'.

The triad of impairments can occur on its own but is very often associated with other developmental disorders, including, among others, all degrees of learning disability, specific learning disorders, and attention deficit and hyperactivity. Autistic spectrum disorders can also occur together with any kind of physical condition, such as epilepsy, or with chromosomal abnormalities, such as Down's syndrome. Evidence from many studies shows that autistic disorders are due to brain dysfunction. Genetic factors are of major importance, but other physical conditions affecting development of the brain before, during or after birth may also be involved. In the great majority of cases, autistic disorders are present from birth or become apparent within the first three years of life.

The triad is present throughout life, but those who are most able and have useful skills often learn through intellectual effort to adjust to the social world and become independent as adults. Some make major contributions in their special fields. Most of those who have learning disability as well as the triad remain disabled and need help all their lives. However, all can benefit from education tailored to their needs.

### Inheritance patterns

Ongoing research suggests that the pattern of inheritance is complex, involving a number of different genes.

### Pre-natal diagnosis

None



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## **SUPPORT GROUPS**

### The National Autistic Society

The National Autistic Society  
393 City Road  
London  
EC1V 1NG  
Tel 0870 600 8585 Helpline (10am - 4pm, Mon - Fri) 020 7833 2299  
Fax 020 7833 9666  
E-mail: [nas@nas.org.uk](mailto:nas@nas.org.uk)  
Web Site: <http://www.nas.org.uk>

The Society is a National Registered Charity No. 269425, formed in 1962. It offers: information, advice and support; training courses and conferences; and the promotion of research. It publishes a journal, 'Communication', three times a year and has a wide range of information available, details on request. Please send SAE. The Society represents over 10,000 members.

### Scottish Society for Autism

Scottish Society for Autism  
Hilton House  
Alloa Business Park  
Whins Road  
Alloa  
FK10 3SA  
Tel 01259 720044  
Fax 01259 720051  
e-mail [autism@autism-in-scotland.org.uk](mailto:autism@autism-in-scotland.org.uk)  
Web Site: <http://www.autism-in-scotland.org.uk>

The Society is a Scottish Charity No. SC 009068, founded in 1968. It offers: support, information, advice and training for parents, carers and professionals; and promotes and provides autism-specific education, care, support and opportunities for people of all ages with autism/Asperger syndrome in Scotland. It publishes 'In Touch' magazine and 'Jigsaw' newsletter three times a year and has a wide range of information available, details on request. The Society has over 800 members.

### Autism Research Ltd – the International Autistic Research Organisation

The International Autistic Research Organisation  
49 Orchard Avenue  
Croydon  
CR0 7NE  
Tel 020 8777 0095 (24 Hours)



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Fax 020 8776 2362  
e-mail: [iaro@lineone.net](mailto:iaro@lineone.net)  
Web Site: <http://www.charitynet.org/~IARO/>

The Organisation is a National Registered Charity No. 802391. It offers individual and general information on autism to parents, carers or teachers. It publishes a newsletter approximately 4 times a year and has information available, details on request. The Organisation has about 300 members including those overseas.

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The information above is from Contact A Family's website ([www.cafamily.org](http://www.cafamily.org)). Contact a Family is a UK charity which helps families who care for children with any disability or special need. They are a main source of information about rare disorders and are able to assist affected adults as well as children.

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## Local information and support

**Borders Asperger & Autism Group Support** - B.A.A.G.S. offers parents, relatives, friends and anyone with an interest in Asperger syndrome, autism or related behaviour. It is a group run by volunteer parents and people who work with autistic children. The aim of BAAGS is to make people aware of the condition and the effects it has on everyone, the teachers, the families the neighbours etc. it is important for the person with autism to be allowed the opportunity to have the correct care and attention individually planned around them.

Meetings are held on the last Monday of every month at the King's Arms Hotel, Melrose at 7.30pm. All welcome.

Telephone : 01896 668961

**Lothian Asperger Syndrome Support Group** - the group provides support for parents and adults with Asperger's Syndrome. There are two support groups within Lothian :

Parents of Autistic Spectrum Disorder Adults - email [sw011c9334@blueyonder.co.uk](mailto:sw011c9334@blueyonder.co.uk)

and

Edinburgh & Lothian Asperger Society - email : [info@elas-scot.org.uk](mailto:info@elas-scot.org.uk), website : [www.elas-scot.org.uk](http://www.elas-scot.org.uk)



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## Useful websites for further information

**Asperger Norfolk** – although geared towards people in the Norfolk area, this site has a large amount of useful information.

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

## Asperger's UK and Asperger's Scotland

Link to online discussion groups for people with Asperger's, their friends and families

<http://www.smartgroups.com/group/findgroup.cfm?CID=244087>

**Asperger's Syndrome** – a site for University students with autism or Asperger's syndrome in the UK

<http://users.wpi.edu/~trek/aspergers.html>

## O.A.S.I.S – Online Asperger Syndrome Information and Support

<http://www.udel.edu/bkirby/asperger/>

## Autism Network International

<http://ani.autistics.org/>

## Books for further reading

These can be purchased from bookshops, or borrowed through your local public library. If your local library does not have a copy in stock, they can arrange to obtain a copy on Inter-Library Loan for you to borrow, for a charge of around 50p.

### **Asperger's Syndrome** by Tony Attwood

A Guide for Parents and Professionals

'Parents, other family members and professionals have to understand the point of view of people with Asperger's Syndrome in order to work with them effectively. The strength of Tony Attwood's book is that he has made the essential imaginative leap into the Asperger world. He has real empathy with the children and adults he writes about and his sympathy, knowledge and common sense come through on every page. Readers will appreciate the detailed discussions of the problems people with the syndrome will encounter and the practical suggestions for helping to overcome or compensate for them. This is a book to be read and consulted over and over again.'

- *From the foreword by Lorna Wing*

Tony Attwood's guide will assist parents and professionals with the identification, treatment and care of



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both children and adults with Asperger's Syndrome. The book provides a description and analysis of the unusual characteristics of the syndrome and practical strategies to reduce those that are most

conspicuous or debilitating. Beginning with a chapter on diagnosis, including an assessment test, the book covers all aspects of the syndrome from language to social behaviour and motor clumsiness, concluding with a chapter based on the questions most frequently asked by those who come into contact with individuals with this syndrome. Covering the available literature in full, this guide brings together the most relevant and useful information on Asperger's Syndrome, incorporating case studies from the author's own practical experience as a Clinical Psychologist, with examples of, and numerous quotations from people with Asperger's Syndrome.

Jessica Kingsley Publishers, 1998  
ISBN : 1-85302-577-1  
240 pages. £12.95

**Freaks, Geeks and Asperger Syndrome** by Luke Jackson  
A User Guide to Adolescence

Have you ever been called a freak or a geek? Have you ever felt like one? Luke Jackson is 13 years old and has Asperger Syndrome. Over the years Luke has learned to laugh at such names but there are other aspects of life which are more difficult. Adolescence and the teenage years are a minefield of emotions, transitions and decisions and when a child has Asperger Syndrome, the result is often explosive.

Luke has three sisters and one brother in various stages of their adolescent and teenage years but he is acutely aware of just how different he is and how little information is available for adolescents like himself.

Drawing from his own experiences and gaining information from his teenage brother and sisters, he wrote this enlightening, honest and witty book in an attempt to address difficult topics such as bullying, friendships, when and how to tell others about AS, school problems, dating and relationships, and morality.

Luke writes briefly about his younger autistic and AD/HD brothers, providing amusing insights into the antics of his younger years and advice for parents, carers and teachers of younger AS children. However, his main reason for writing was because "so many books are written about us, but none are written directly to adolescents with Asperger Syndrome. I thought I would write one in the hope that we could all learn together".

Jessica Kingsley Publishers, 2002.  
ISBN : 1-84310-098-3  
224 pages. £12.95.



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## **Asperger Syndrome and Difficult Moments** by Brenda Smith Myles and Jack Southwick Practical Solutions for Tantrums, Rage and Meltdown

Written for parents and professionals, *Asperger Syndrome and Difficult Moments* offers practical solutions to the day-to-day challenges facing individuals with Asperger Syndrome and their families. The book discusses clearly and concisely how to deal with tantrums, meltdowns and difficult behaviour from children and young people with Asperger Syndrome, looking in particular at the role of antecedent behaviours, which signal the beginning of a meltdown, as identified through functional assessment.

Topics covered include:

- the characteristics of Asperger Syndrome and their impact on behaviour
- stages of the meltdown cycle
- the role of antecedent behaviours
- functional assessment
- strategies promoting social skills development, including self-awareness, self-calming and self-management
- solutions for parents, including organization and support, and daily routines.

The book's main focus is on the various stages of the meltdown cycle and functional analysis as a means of determining why behaviours occur. This is followed by a set of practical strategies that promote social skills development, including self-awareness, self-calming and self-management. The book concludes with a chapter written specifically for parents, which offers concrete and easy-to-follow steps for developing a home plan that addresses agreement on the causes of problem behaviours, family organization and support, the LASTING word and designing a daily routine. Accompanying the clear and user-friendly writing style are a number of helpful reporting forms and other instruments that may be used by schools and parents as they work to reduce or eliminate such behaviour in children and young people with Asperger Syndrome.

Jessica Kingsley Publishers, 1999.

ISBN : 0-96725-143-5

112 pages. £14.95.

Jessica Kingsley Publishers produce a wide range of books dealing with autistic spectrum disorders. They produce a catalogue several times a year, and have a website at [www.jkp.com](http://www.jkp.com). They can be contacted at 116 Pentonville Road, London N1 9JB, England  
Tel: 020 7833 2307 Fax: 020 7837 2917

Snip information sheets can be produced in a number of formats : in Braille, on tape, on disk or CD, and in community languages. Please contact us on **0131 536 0360** if you would like this information sheet in a different format.