



SNIP
14 Rillbank Terrace
Edinburgh
EH9 1LN

Tel : 0131 536 0583
Fax : 0131 536 0583
Textphone : 0131 536 0360
Email : snip@btinternet.com

AUTISTIC SPECTRUM DISORDERS

Autism

by Dr Trisha MacNair and Dr Rob Hicks

What is it?

Autism is a lifelong neuro-developmental disability that affects the way a person communicates, and severely limits their ability to relate to others in a meaningful way, develop friendships or understand other people's feelings.

People with autism find it hard to make sense of the world, which can appear chaotic, with no clear boundaries, order or meaning to anything.

Autism is often referred to as a spectrum disorder because of the variation in type and severity of problems a child may experience.

What are the problems?

People with autism have a three types of impairment : in social interaction, social communication (verbal and non-verbal - they don't understand the meaning of gestures, facial expressions or tone of voice) - and imagination.

In general there may be:

- a failure to develop normal speech
- an absence of normal facial expression and body language
- a lack of eye contact
- a tendency to spend time alone
- a lack of imaginative play
- repetitive behaviour
- obsession with particular objects or routines

These behavioural difficulties can cause a great deal of stress for members of the family.

As many as 75% of people with autism have accompanying learning disabilities and 15-30% have seizures.

Some autistic children have an exceptional skill such as an aptitude for drawing, mathematics, or playing a musical instrument.



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Who does autism affect?

Autism affects approximately 5 in 10,000 people with a male to female ratio of 4 to 1. Autistic spectrum disorders are estimated to touch the lives of over 500,000 families throughout the UK.

Although autism can sometimes run in families, the precise cause of autism remains unknown so it is currently not possible to prevent it. Research shows that genetic factors are important. Autism is also associated with a variety of conditions which affect brain development before, during, or very soon after birth. These conditions may trigger autism in a person who is genetically susceptible.

There is no cure for autism. Maximising a child's potential is the goal of treatment. This can be achieved through appropriate specialist education, speech and language therapy - and behavioural therapy. Medication is sometimes recommended when it is felt to be of benefit to the child.

Genetic factors

A strong genetic component in autism is shown by the high number of identical twins both having the condition compared to non-identical twins, and a risk among brothers and sisters of affected people which is 75 times greater than for the general population. Researchers are currently examining a number of chromosome sites that could be implicated, especially on chromosomes 7 and 15.

It is likely that autism occurs with the interaction of a small number of specific genes - and possibly with some external event or factor. These genes have yet to be pinned down but may include the HOXA1 gene, which is active in the brain stem only during development, when the first neurons are forming in the embryo.

There is no simple screening test to identify those people carrying genes which might increase susceptibility to autism, and no prenatal screening available.

The information above is from the BBC Health (www.bbc.co.uk/health) and Contact A Family's (<http://www.cafamily.org/>) websites. 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. To contact them, telephone : **0808 808 3555**.



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NATIONAL SUPPORT GROUPS

The National Autistic Society

The National Autistic Society
393 City Road
London
EC1V 1NG
Tel 0845 070 4004 Helpline 020 7833 2299
Fax 020 7833 9666
E-mail: 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.

NAS Scotland

Central Chambers
1st floor, 109 Hope Street
Glasgow G2 6LL
Tel : 0141 221 8090
Email : scotland@nas.org.uk

Scottish Society for Autism

Scottish Society for Autism
Hilton House
Alloa Business Park
Whins Road
Alloa
FK10 3SA
Tel 01259 720044
Fax 01259 720051
Email : autism@autism-in-scotland.org.uk
Website: <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.



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LOCAL INFORMATION AND SUPPORT

BORDERS

Borders Aspergers and Autism Group Support

Meet last Monday of every month at 7.30pm in the Kings Arms Hotel in Melrose. All welcome.

Tel : 01896 668961
Email : baagsmail@yahoo.co.uk
www.baags.co.uk

EAST LOTHIAN

Roundabout Support Group

The Roundabout Group is a support group for parents and families of children affected by ADHD, Aspergers Syndrome, Autism Spectrum Disorders, Tourette Syndrome, Dyspraxia and Dyslexia. The group is also a social contact point for parents and carers to meet with other parents who are in similar circumstances. There is also a youth club run alongside the support meetings which is open to children whose parents attend the support group. The support group meets every 2 weeks on a Thursday evening from 6.30pm - 8.30pm at the Early Years Centre in Tranent.

Telephone: 01875 615415
Email: roundabout@tragus.fsnet.co.uk
Website: <http://health.groups.yahoo.com/group/theroundabout>

EDINBURGH

Lothian Autistic Society

Unit 22
Castlebrae Business Centre
40 Peffer Place
Edinburgh
EH16 4BB
Telephone : 0131 661 3834
Email : office@lothianautistic.org
Web : www.lothianautistic.org

Support and information for families with autistic children. Trying to improve facilities/education for children/people with autism and to increase public awareness of autism. Meetings open to parents, professionals and anyone with an interest in autism.



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The Action Group

Norton Park
57 Albion Road
Edinburgh
EH7 5QY

Telephone : 0131 475 2315
Fax : 0131 475 2316
Email : advice@actiongroup.org.uk
Web : www.actiongroup.org.uk

Activities include campaigning; information and newsletters; supported accommodation; sitter service; welfare rights advice and worker; holidays; playschemes; leisure schemes; employment project; family information & support service; siblings group; ADHD group; autism group

Spectrum

154 McDonald Road
Edinburgh
EH7 4NN
Telephone : 0131 469 2850

Offer teaching programmes (early intervention) for pre-school children with autism, and guide families in using these with their child. The project offers support at home, nursery or a children's centre, depending on the needs of the child and family. Covers the Edinburgh area.

FIFE

Fife Action on Autism

Web : www.fifeactiononautism.org.uk
Email : enquiries@fifeactiononautism.org.uk

MIDLOTHIAN

Midlothian Parents Special Needs Forum

c/o Joan Griffiths
Midlothian Council
Fairfield House
8 Lothian Road
Dalkeith
EH22 3ZN
Tel : 0131 271 3645



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Forum meets 6-8 times a year in Midlothian to discuss parents' concerns, share information and provide mutual support. The forum is also an opportunity to comment on changes in services and planning, with guest speakers from the council giving presentations etc.

Monthly newsletter with notes of meetings and local information – can provide links for parents of a child with a specific condition e.g. autism to make contact.

WEST LOTHIAN

Tuesday Parent Group for Children with Communication Difficulties or Autism

Child Development Centre
Beatlie Campus
Livingston
EH54 5EJ
Tel: 01506 777 598
Email: louise.jarman@wlt.scot.nhs.uk
Web: www.beatliecampus.org.uk

Meets weekly during term time in the Child Development Centre on Tuesdays from 9.30am to 11.30am. The group is led by a parent of a child with autism. A crèche is available. There is access to a lending library on autism and speakers are arranged as required.

DISABILITY LIVING ALLOWANCE AND AUTISTIC SPECTRUM DISORDER

Disability Living Allowance (DLA) is a benefit available to help with personal care and/or getting around.

DLA is available to children over the age of three months and adults with a disability under 65 years old. Many people have successfully claimed DLA because their child needs help with things like washing, dressing or going to the toilet; needs someone to keep an eye on them during the day; needs someone to keep an eye on them at night; cannot get around outdoors without supervision or has a severe mental impairment. **This extra care has to be over and above the care that a child of the same age would normally require.**

Claiming DLA does not affect any other benefits you may receive and is not linked to savings. To apply, you need to get the form **DLA1A**, specifically for children. You can get this form by ringing the Disability Benefits Enquiry Line on **0800 882200**.

The form is very long, and can be a bit daunting to complete. Some parents find filling out the form very depressing, as it focuses on many of the things your child is not able to do. It is important to put in



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everything that is involved in caring for your child, as the person assessing your claim may not have any expertise or knowledge of autism, or of what is involved in the care of a child with autism.

Help with filling out the form is available from the SNIP Information and Advocacy Workers; from your local welfare rights office or Citizen's Advice Bureau and from the Disability Alliance advice line - **0800 882200** (Monday - Friday 8.30 am - 6.30 pm).

If you would like to know more about claiming DLA, or would like to make an appointment with one of the Information and Advocacy Workers for help with the form, please give us a call on **0131 536 0583**.

USEFUL WEBSITES FOR FURTHER INFORMATION

Autism UK

<http://www.autism-uk.ed.ac.uk/>

Autism Awareness

<http://www.autism-awareness.org.uk/>

About Autism Written by parents for parents

<http://www.aboutautism.org.uk/>

Autism in Mind

<http://www.autism-in-mind.org.uk/>

Autistic Net

<http://www.autistic.net/>

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 small charge.

I am Special by Peter Vermeulen.

Introducing Children and Young People to their Autistic Spectrum Disorder.

A workbook developed by Peter Vermeulen and already used extensively with young people with autism spectrum disorder. The workbook is designed for a child to work through with an adult - parent, teacher or other professional. Unlike other books, its content and layout are devised especially for children who read, think and process information differently. I am Special is divided into two parts. The first is a theoretical introduction which explains how to inform children that they have autism or



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Asperger Syndrome and how to use the worksheets with groups or individuals. The second part consists of a series of worksheets which the child works through with an adult to create a unique and personal book about him or herself. It includes a series of exercises that present autism positively. They strike a balance between general facts, information about autism and personal information, covering the strengths an autistic person may have as well as the difficulties they may face.

I am Special can be used with young people over the age of ten years. Not only is it an excellent source of information for the autistic child; it can be the first step in a process of counselling or psychotherapy or the springboard for a discussion group on autism.

Jessica Kingsley Publishers, 2000.
ISBN : 1-85302-916-5
240 pages. £15.95

Playing, Laughing and Learning with Children on the Autism Spectrum by Julia Moore.

A Practical Resource of Play Ideas for Parents and Carers.

Parents of young children newly diagnosed as on the autism spectrum are often at a loss for ideas about how best to help their child. They feel dismayed and 'shut out' by their child and are often also having to grapple with language and behaviour problems. *Playing, Laughing and Learning with Children on the Autism Spectrum* is not just a collection of play ideas; it shows how to break down activities into manageable stages, and looks at ways to gain a child's attention and motivation and to build on small achievements. The use of case studies illustrates how problems of ritual and obsession can be used and redirected positively and shows how to structure play activities and overcome communication barriers by using picture cards. Each chapter covers a collection of ideas around a theme, including music, art, physical activities, playing outdoors, puzzles, turn-taking and using existing toys to create play sequences. There are also chapters on introducing reading and making the most of television. The ideas are useful both for toddlers and primary age children who are still struggling with play.

Jessica Kingsley Publishers, 2002.
ISBN : 1-84310-060-6
288 pages. £12.95

How to Live with Autism by Christine Williams and Barry Wright
Practical Strategies for Parents

This accessible and valuable introduction to caring for a child with autism is an ideal resource for teachers and members of a child with autism's immediate and extended family. In clear and simple language, with many illustrations, the authors tackle common problems experienced in everyday routines such as eating, sleeping and going to the toilet, as well as how to cope with aggression and tantrums, preoccupations and compulsions and how to enable better communication and socialising. Based on up-to-date research and using many case examples, the authors consider step-by-step why each problem may be happening and suggest a number of solutions.



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Jessica Kingsley Publishers, May 2004.
ISBN : 1-84310-184-X
224 pages. £13.95

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. They can be contacted at 116 Pentonville Road, London N1 9JB, England
Tel: **020 7833 2307** Fax: 020 7837 2917

Notes :

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.