



Family Information Services and Resource Pack

Autism



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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.

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

Services

Autism West Midlands

In Shropshire there is an autism development team who work with families/carers and professionals working with children and young people with autism aged 0-18 years. This service is funded by Shropshire Council and Shropshire PCT and is free to families and professionals working with children in the Shropshire Council area. For families and carers they offer information, guidance and support by appointment at advice sessions around the county and targeted intervention/support where appropriate. Families should in the first instance contact the Autism West Midlands Information helpline who can refer to the Shropshire team. The helpline can also register parents to the Shropshire mailing list for details of other Shropshire autism events including:

- Rising to the Challenge parent workshops and other workshops and conferences
- Family events during the school holidays

For professionals they offer

- Autism awareness training and other training tailored to particular service needs
- Joint work with service development
- Participation in strategic developments in Shropshire

Telephone: 01743 210940

General Enquiries: 0121 450 7582

Helpline: 0303 0300 111

Email: hello@autismwestmidlands.org.uk

Website: http://www.autismwestmidlands.org.uk/shropshire

Shropshire Autonomy

Autonomy is a free Shropshire based self-help and social group for young people (18 and over) and adults who have Asperger's Syndrome (AS), (diagnosed or undiagnosed). Young people aged 16-18 can attend the Board Games Club with an adult to support him/her. Shropshire Autonomy offer:-

- Opportunities to meet others with Asperger's syndrome
- Telephone advice and support (for people with AS and/or their parents. partners/carers)



- Friendship and understanding
- Social events and activities
- A free bi-monthly newsletter by mail or email
- A range of charged-for Autonomy Plus+ services including consultancy, awareness training, mentoring, help with claiming benefits, pre- and post- diagnostic support and professional help

Website: http://www.shropshireautonomy.co.uk

Shropshire Autism Hub

Shropshire autism hub offers friendly helpful advice on everything autism, at a free drop in for carers and family members on Thursday 12pm - 4pm.

This hub is for people on the autism spectrum, including those with Asperger's syndrome. Carers are very welcome too. The hub takes place at Louise House, Roman Road, Meole Brace, Shrewsbury. Friendly advice and refreshments will be available.

Website: http://shropshireautismhub.moonfruit.com/

Woodlands Outreach Autism Spectrum Support

Provides assessment, information, guidance and support to mainstream schools in Shropshire for pupils with needs related to the Autism Spectrum. The team consists of Autism Spectrum Advisory Teachers and a specialist practitioner.

The following advice and support is available for purchase from the Autism Spectrum Advisory Support Team

Whole School Strategic Support Relating to the Autism Spectrum

- Supporting schools in carrying out an 'Evaluation of Current Practice in Relation to the Autism Spectrum' to enable the school to enhance their current practice
- Supporting schools in carrying out a 'Sensory Audit' of the school environment to help meet the needs of pupils with sensory sensitivities.
- Supporting schools in implementing provision mapping for children on the Autism Spectrum
- Supporting identified Key Workers for children on the Autism Spectrum in developing their role
- Supporting the SENCo in matters related to the Autism Spectrum
- Advice on supporting pupils on the Autism Spectrum during transition times and unstructured times (break times, lunchtimes, homework clubs & extra-curricular activities)
- Meeting with the senior leadership team and/or school governors to discuss matters in relation to the Autism Spectrum
- Awareness raising sessions about the Autism Spectrum for mainstream pupils. This
 may include small groups of pupils, whole classes, tutor groups, year groups or other
 groups as requested

Individual Support for Children on the Autism Spectrum or with Needs Related to the Autism Spectrum



- Provide individual case support through observations, one to one work and feedback
- Develop pupils' social interaction skills through social skills groups, comic strip work, social stories and other approaches
- Develop pupils' awareness of their own emotions and the emotions of others. This
 may be within social skills groups or may be through a series of individual support
 sessions
- Provide sample resources for use with individual pupils (timetables, key rings, cue cards, reward systems, emotion monitors and other visual support approaches)
- Carry out 'Stressor Assessments' for individual pupils and provide feedback
- Attend Annual Reviews, Early Intervention or other meetings related to the child, provided that sufficient notice is given
- Provide individual reports following an initial period of assessment or intervention package
- Provide individual reports as part of an application for Statutory Assessment or as part of the annual review process
- Monitor and review pupils on SEN Support or who have an Education, Health and Care Plan (EHCP)
- Provide advice in relation to IEPs
- Provide advice, strategies and individual support sessions in relation to behavioural issues
- Support pupils in understanding their Autism Spectrum diagnosis
- Liaise with other agencies
- Liaise with signpost, support and advise parents
- Meeting parents and/or carers
- Supporting pupils with transitions between year groups or schools; e.g. Year 6 to Year 7.

http://www.woodlandscentre.org/woodlands-outreach/austim-learning-behaviour/autism-advisory-service/

Shropshire Disability Network

Shropshire Disability Network (SDN) was formed in 2008 to provide a powerful collective voice for disabled people across Shropshire.

SDN holds quarterly Open Meetings (which are open to guests) to discuss current disability issues in Shropshire, and periodically releases an extensive Newsletter of events and information.

You can join the SDN as a full member to be kept up to date with what's going on, on a regular basis. Membership is free.

Email: info@shropshire-disability.net

Website http://shropshire-disability.net/

Ambitious About Autism

This is a national charity for children and young people with autism. They provide services, raise awareness and understanding, and campaign for change. The vision is to make the ordinary possible for children and young people with autism and our mission is to help them to learn, thrive and achieve.

Website: http://www.ambitiousaboutautism.org.uk/



National Autistic Society

They are the leading UK charity for people on the autism spectrum (including Asperger syndrome) and their families. They provide information, support and pioneering services, and campaign for a better world for people with autism.

Website: http://www.autism.org.uk/

Autism West Midlands Connect

Connect is an online social network built for people with autism, their families and professionals. The idea was to bring together the unique experiences of each individual in the autism world and allow them to share their thoughts, ideas and stories with others. The hope that this will help people to understand the perspective of other members of the autism community; professionals learning from parents, parents learning from adults with autism and so on.

Connect is aimed at adults and adolescents but usage depends on a person's level of understanding and ability. The site seeks to reduce the vulnerability of users with several safety features. They constantly monitor the site and moderate the content to ensure it remains suitable. They also have an extensive site guide and code of conduct so people can use the site without prior knowledge of social networking sites. There is also a lenient complaints procedure, with an emphasis on benefit of the doubt, and procedures in place to mediate and explain, rather than to judge or to punish. They have a zero tolerance approach to bullying or abuse.

The site itself offers users a truly social experience, with status updates, member profiles and family pages. Users can also like and share statuses, comment on them and even send a hug when someone needs a bit of cheering up.

There is also a question and answer section where the variety of experience of users comes into its own, with experts in various areas offering advice and guidance to others - be they parents, professionals or adults with autism. The Service Directory also offers a chance for users to share knowledge and rate and review services they have used. Finally, the events page is a catalogue of great events running that parents can search for by area.

There is also information resources, visual resources and high quality e-learning packages all available free of charge.

You can visit the site here: connect.autismwestmidlands.org.uk

Telephone: 0121 450 7582

Email: connect@autismwestmidlands.org.uk Website: https://autism-connect.org.uk/

PEACH

PEACH is a UK national charity that provides information and support to parents of children with Autism to give better choice. PEACH advocates the use of early behavioural intervention programmes (applied behaviour analysis). These programmes aim to enhance intellectual, academic, social and emotional behaviours so that children can take better advantage of opportunities available to them.



Telephone 01344 882248 Email info@peach.org.uk Website http://www.peach.org.uk

Parent and Carer Council (PACC)

A group of parents and carers of children with disabilities or additional needs including:

- Physical disabilities
- Medical conditions
- Psychological conditions
- Learning difficulties

Aims to make parents and carers aware of developments that affect their children and to give them a voice in influencing these developments.

Telephone: 0845 601 2205

Email: enquiries@paccshropshire.org.uk Website: http://www.paccshropshire.org.uk/

Oasis Group - Parent and Carer Council Shropshire.

PACC supports a number of OASIS support groups which any parent of a child with a disability or additional need is welcome to attend. The meetings provide an opportunity for parent/carers to meet each other and to share their experiences.

We are currently hosting a daytime meeting in Shrewsbury on a monthly basis at the Shrewsbury Baptist Church. These are held on a Monday between 10.00am and 12.00pm. Tea, coffee and biscuits are available, as well as the PACC library to borrow from.

There is an evening meeting held at Monkhouse Granary, nr. Battlefield, Shrewsbury. This meeting is held monthly on a Wednesday evening between 8.00pm and 10.00pm.

Telephone: 0845 601 2205

Email: enquiries@paccshropshire.org.uk Website: http://www.paccshropshire.org.uk/

<u>Information, Advice and Support Service for Shropshire previously Parent</u> Partnership Service

From 1st October 2015 all clients receiving support from the Information, Advice and Support Service and living in Shropshire were transferred to a new provider, Citizens Advice Shropshire. You may have known this service as the Parent Partnership Service based in Telford & Wrekin CVS. The service will be known as Shropshire Information, Advice and Support Service (Shropshire IASS)



Shropshire IASS acts as a point of contact for parents and carers of children and for young people aged up to 25 who have SEND or related health and social care needs. The service provides:

- impartial information and advice about matters relating to special educational needs (SEN) or disabilities (D), including matters relating to health and social care and advice and support on the take up and management of Personal Budgets.
- children and their parent/carers and young people with the information and support to enable them to participate in decisions about their individual support

You can contact Shropshire IASS on 01743 280019. The referral line is staffed Monday to Friday 10am till 4pm. You can also visit the CAS website at www.cabshropshire.org.uk ring Citizens Advice Shropshire on 03444 99 11 00 or call in at one of their offices in Ludlow, Oswestry and Shrewsbury.

Telephone: 01743 280019

Early Bird Plus

Early Bird Plus is for parents whose child has received a later diagnosis of an autism spectrum disorder (ASD) and is aged 4-8 and in Early Years or Key Stage One provision.

The programme addresses the needs of both home and school settings by training parents/carers together with a professional who is working regularly with their child, the aim being that a child will be given consistent support. We work to build both parents' and professionals' confidence and encourage them to problem solve together.

Tel: 01226 779218 Fax: 01226 771014

Email: earlybird@nas.org.uk

Website: http://www.autism.org.uk/earlybird

Shropshire Spectrum Support Group

Group for parents/carers of a child with autism, Asperger's Syndrome, ADHD, and who would like to meet other parents/carers to share ideas, worries and concerns in a friendly and welcoming setting. Free membership - £1.00 per meeting

Telephone: 07852 691774 Email: netgriffiths@gmail.com Website: http://spectrum.t83.net/

Young Minds

Are you worried your child may have autism or Asperger Syndrome? Or has your child been diagnosed with autism or Asperger Syndrome and you are wondering what to do next? YoungMinds is here to help and support. YoungMinds is the UK's leading charity committed to improving the emotional wellbeing and mental health of children and young people. Driven by their experiences they campaign, research and influence policy and practice.



They have information about the symptoms, diagnosis and help available for autism and Asperger Syndrome, especially for parents and carers, with links to other organisations who can help. They're also here to listen. If you want to talk to someone in confidence about your worries, you can contact the YoungMinds Parents' Helpline for free on **0808 802 5544.**

Main Website: http://www.youngminds.org.uk/ Email: ymenquiries@youngminds.org.uk

Helpline: 0808 802 5544

Patient Info - Autism Pages

Patient is the web's leading independent health platform, established for over 15 years. With more than 18 million visits a month, it is a trusted source of information for both patients and health professionals across the globe.

The site contains over 4000 health information leaflets, a wellbeing centre, a free health check, and thousands of discussion forums. It is accredited by The Information Standard and NHS England's quality mark.

http://patient.info/health/autistic-spectrum-disorders

NHS Choices - Autism Pages

NHS Choices (http://www.nhs.uk/pages/home.aspx) is the UK's biggest health website. It provides a comprehensive health information service to help put patients in control of their healthcare.

The website helps make choices about health, from decisions about lifestyle, such as smoking, drinking and exercise, to finding and using NHS services in England.

NHS Choices - Introduction to Autism

http://www.nhs.uk/conditions/Autistic-spectrum-disorder/Pages/Introduction.aspx

Research Autism

Research Autism is the only UK charity dedicated to the promotion of high-quality research into autism treatments, therapies and other approaches. Their vision is of a world in which people on the autism spectrum are no longer excluded, and where they and their families are able to enjoy a good quality of life

Telephone 020 3490 3091 Email info@researchautism.net Website: http://researchautism.net/

Autism Education Trust

The Autism Education Trust believes that all children and young people with autism should receive an education which enables them to reach their individual potential to engage in



society as active citizens (and that individuals, families and professionals are informed, supported and equipped to enable this to be achieved). The Autism Education Trust is dedicated to coordinating, supporting and promoting effective education practice for all children and young people on the autism spectrum.

Website: http://www.autismeducationtrust.org.uk/

Autism Alliance

The network of 18 autism charities supports many thousands of adults and children with autism across the UK. In the UK, more than 1 in 100 people with autism risk being excluded from their own communities because they are misunderstood. They want to use there knowledge and understanding to build autism-friendly communities, raise general awareness of autism and provide quality information.

http://www.autism-alliance.org.uk/

ASD Friendly

ASD Friendly is a close-knit online community forum of parents and carers of people with Autism and Asperger's Syndrome. ASD Friendly brings together to share tips, vent frustrations and generally have a laugh about things that other people would never understand. Caring for a disabled child is difficult and rewarding; it's good to know that families don't need to do it all alone.

http://www.asdfriendly.org/

Wrong Planet

Wrong Planet chat and forum for Autistic people and families

http://wrongplanet.net/

Cheshire Autism

This guide provides a brief overview of the sorts of mental health problems children with autism may experience; information and advice on preventing and reducing mental health problems and promoting emotional wellbeing;

http://www.cheshireautism.org.uk/media/3316/NAS%20You%20Need%20To%20Know%20Mental%20Health.pdf

All In

All In offers fun, friends and activities for children and young people with disabilities or additional needs. The 'All In' programme provides different opportunities for children/young people with different needs. Some activities may not be suitable for every child/young person. Children need to apply to become a member before they can attend activities. Application forms can be found here



http://new.shropshire.gov.uk/the-send-local-offer/parentcarers/social-care/short-breaks-activities/all-in-programme/

Cineworld Shrewsbury

Cineworld, Old Potts Way, Shrewsbury, SY3 7ET, host an Autism Friendly Screening at 11:00am on the 1st Sunday of every month, see the website for details.

Website: https://www.cineworld.co.uk/blog/autism_friendly_screenings

Resources

Local Offer

Local Authorities have an obligation to publish a Local Offer, setting out in one place information and provision they expect to be available across education, health and social care for children and young people in their area who have SEN or who are disabled, including those who do not have education, health, and care (EHC) plans. In setting out what they 'expect to be available', local authorities should include provision which they believe will actually be available (SEND Code of Practice 4.1)

Shropshire's Local Offer is designed to help families, children, young people and professionals to support those with special educational needs or disabilities to find accurate and appropriate information so that they can make positive decisions about their lives.

Website: http://new.shropshire.gov.uk/the-send-local-offer/

The Autism Directory

Helping autism families get the help they need. Find autism friendly resources in your local area and beyond.

Website: http://www.theautismdirectory.com/

<u>Autism West Midlands – Books and Resources (costs involved)</u>

http://shop.autismwestmidlands.org.uk/collections/books-resources

<u>Autism and Asperger's syndrome: information for parents, carers and anyone</u> who works with young people from the Royal College of Psychiatry.

This is one in a series of leaflets for parents, carers and professionals working with young people entitled *Mental Health and Growing Up*. This leaflet gives details about Autism and Autism Spectrum Disorders, as well as offering practical advice about how to get help.

http://www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/autismandasperg erssyndrome.aspx



NICE Guidelines on Autism

This guideline covers the recognition, referral and diagnosis of autism in children and young people from birth up to 19 years.

https://www.nice.org.uk/guidance/cg128/chapter/Introduction

<u>Mindreading DVD: Teaching emotion-recognition to people with autism spectrum</u> conditions

These cd roms are for children and adults with autism spectrum conditions to use as teaching tools to help them learn about emotions. The DVD-ROMs have a comprehensive set of emotional expressions in the face and the voice, as produced by actors, and use computer-game formats to help the user learn this information that they usually find difficult.

http://www.jkp.com/mindreading

The National Autistic Society Publications

http://www.autism.org.uk/shop/books.aspx

What is Autism? (Free Publication)

http://www.autism.org.uk/products/leaflets/what-is-autism.aspx

After Diagnosis – Information for parents (Free publication)

http://www.autism.org.uk/products/leaflets/after-diagnosis.aspx

National Centre for Mental Health

Autism Spectrum Disorder – Information for parents (downloadable leaflet or complete the order form to receive a free copy through the post) http://ncmh.info/leaflets/

Education

Autism Education Trust

These resources could help parents and carers identify what is important in the education of their child with autism or Asperger syndrome. Parents and carers can use these resources to talk to staff in schools about how best they can work together and also help the parents find the best school for their child.

http://www.aettraininghubs.org.uk/parent-guide/



Keeping Children Safe from Abuse

NSPCC - The Underwear Rule and Help Keep Children Safe from Abuse

Teach your child the Underwear Rule and help protect them from abuse. It's a simple way that parents can help keep children safe from sexual abuse – without using scary words or even mentioning sex. Specific booklet to help parents of children with Autism find out more about the Underwear Rule.

https://www.nspcc.org.uk/globalassets/documents/advice-and-info/underwear-rule-parents-guide-children-autism.pdf

Travel

<u>Airport Aware - Travel advice for parents and carers of children on the Autistic</u> Spectrum

To help your journey Manchester Airport have create terminal specific travel booklets for parents and carers with children on the Autistic Spectrum. This relates specifically to Manchester airport but there is some good advice about general travel.

https://www.manchester-airport-guide.co.uk/disabled-facilities.html

Terminal 1 guide http://mag-umbraco-media-live.s3.amazonaws.com/1008/awarenessplusbookletplust1.pdf

Terminal 2 guide http://mag-umbraco-media-live.s3.amazonaws.com/1009/awarenessplusbookletplust2.pdf

Terminal 3 guide http://mag-umbraco-media-live.s3.amazonaws.com/1010/awarenessplusbookletplust3.pdf

Holidays: - Preparation and practicalities

Planning a holiday is exciting and sometimes stressful. If you have a child with an autism spectrum disorder (ASD) a trip away may involve extra organising and preparation. This guide will help to prepare.

http://www.autism.org.uk/About/Family-life/Holidays-trips/preparation

Technology

<u>Using Technology – Guidance for Parents</u>

Using technology – computers, gamers and other devices - is a popular leisure time activity for people with autism. Here we provide practical guidance to parents of children with autism to help them get the most benefit from technology and avoid associated problems

http://www.autism.org.uk/technology



Books

Freaks, Geeks & Asperger Syndrome by Luke Jackson

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. 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."

https://www.amazon.co.uk/Freaks-Geeks-Aspergers-Syndrome-Adolescence/dp/1843100983

Asperger Syndrome in Adolescence by Liane Holliday Willey

Reflecting the views of parents, professionals and those with Asperger Syndrome themselves, this book tackles issues that are pertinent to all teenagers, such as sexuality, depression and friendship, as well as discussing topics like disclosure and therapeutic alternatives that are more specific to those with AS. This book aims to make the transition from child to adult as smooth as possible, and is an essential survival guide to adolescence.

http://www.jkp.com/uk/asperger-syndrome-in-adolescence.html

COPING: A survival guide for people with Asperger's syndrome

Marc knows from the inside what people with Asperger Syndrome need to understand, and much of his knowledge has been acquired through bitter experience. His expressed wish is that others should not have to learn by such a hard route, and that some of his own short term disasters should be avoided by others coming after him

https://www-users.cs.york.ac.uk/alistair/survival/survival.pdf