



After diagnosis.....

"WHAT HAPPENS NOW?"

A guide for parents whose child has just been diagnosed with an Autistic Spectrum Disorder

If you have recently found out that your child has an Autistic Spectrum Disorder (ASD), you may be feeling overwhelmed. Lots of questions will be going through your mind, and you may have a feeling of sadness that your child is not going to be the son or daughter you expected. It is quite natural for you to feel this way. Even if you suspected that your child had an ASD, it may still be upsetting to have it confirmed by a doctor. Some people say it feels like a bereavement with the accompanying grief and feelings of loss, but others find it a relief that their concerns have been acknowledged and they were not being over-anxious parents.

When you receive a diagnosis it is worth remembering that the diagnosis has not changed your child in any way, but it has given you the opportunity to better understand him or her and what help he/she needs. Right now you will want to know what ASD means for your child and the impact it may have on the family as a whole. Some typical questions you are likely to ask are:

- **What is an autistic spectrum disorder?**
- **What caused it?**
- **Is there a cure?**
- **What are the long-term prospects?**
- **Is there someone I can talk to about all this?**
- **What help am I entitled to?**
- **What can I do to help my child?**

In this leaflet we will try to answer those questions, and give you phone numbers for various organisations which might be able to help. There is also a separate sheet with full contact details for the organisations, and other information.

First there are two points we would like to stress:

1. It's not your fault!

Autistic spectrum disorders have nothing whatever to do with the way you have been bringing up your child. Parents of children with ASDs are just like everyone else.

2. You are not alone.

In Britain there are over 500,000 people who are on the autistic spectrum. Each one's behaviour, including your child's, will be unique, but there are underlying common problems which bond the whole group together. Although in the past there was widespread ignorance of autism, today there is a growing awareness of the particular needs and difficulties that children with ASDs face, and many more professionals specialise in ASDs.

1. What is an autistic spectrum disorder (ASD)?

Autistic spectrum disorders such as Autism and Asperger Syndrome are disabilities that affect the way a person communicates and relates to people around them.

There are varying degrees to which people with an ASD are affected, but they will all have in common what is known as the **triad of impairments**. These affect:

- Social interaction (difficulty with social relationships).
- Social communication (difficulty with verbal and non-verbal communication)
- Social imagination (difficulty predicting outcomes or other people's reactions; repetitive behaviour)

Many people with ASDs also have senses which are different, often either intensified or under-sensitive (such as very acute hearing or unusual reactions to touch.)

Specific diagnoses such as 'autism' or 'Asperger Syndrome' are sometimes used instead of 'Autistic Spectrum Disorder'. 'Asperger Syndrome' is generally applied to somebody at the more able end of the autistic spectrum, with normal or above average intelligence and fewer problems with language. 'Autism' is usually applied to those people who also have learning disabilities, but may be used as a short way of referring to the entire autistic spectrum. 'High functioning autism' is another term used to describe some people at the more able end of the spectrum.

Onset of autism is almost always before the age of three years, although high functioning autism/Asperger Syndrome may not be recognised until much later. ASDs affect more boys than girls, and have no class or racial barriers.

2. What causes it?

The cause of autism is still being investigated. However, research suggests that a combination of environmental and genetic factors may account for changes in brain development. It is not a mental illness, nor is it caused by poor parenting or emotional deprivation.

3. Is there a cure?

Autism is not curable but there are a range of educational and other strategies which may result in significant development. As more people are diagnosed with ASDs there is an increasing amount of research being done into potentially helpful strategies.

4. What are the long-term prospects?

Autistic Spectrum Disorders are life long conditions - children do not grow out of them. Unlike most other conditions, the severity of it in adulthood cannot be judged when the child is first diagnosed. There are a number of indicators, such as the development of speech, that provide clues as to the likely outcome, but even these are not conclusive. Experts believe that the first 5 years of the child's life are the most crucial and that is why intensive help before school is important, although intervention at any age is beneficial.

In adulthood, a few at the most severe end of the spectrum will require round-the-clock support. Some others will be unable to go out of their home unaccompanied - they are too vulnerable and don't understand concepts such as money or the dangers of traffic. But many adults with ASDs can live semi-independently or independently. Some are able to hold down a regular job. Some go to university, even become professors. Some marry or live with partners and have children. A lot of progress has been made over the past 20 years in understanding ASD's - and hopefully this will in turn lead to significantly better outcomes in adulthood for those children recently diagnosed.

5. Is there someone I can talk to about all this?

It is often helpful to talk through your feelings with someone who understands what you are going through. Even well meaning friends and relatives sometimes find it hard to accept that anything is wrong: "She's just a bit quiet - she'll catch up"; "you just need to be firm with him". Sometimes your partner, too, has difficulty in understanding how you feel. All this can lead to a sense of isolation and of having no one to talk to who understands.

There are several ways to find someone to speak to who has been through the same experience. One way is to join a local **autism support group**. Whilst it can be daunting going out and meeting new people, it can be well worth making the effort. By getting to know other parents who have children with an ASD you will find people who can understand your difficulties and who will support you and your child in the years to come. Many of them will have already dealt with issues you are facing and can pass on their experiences. The National Autistic Society (NAS) Surrey branch is a support group run by parent volunteers which holds regular meetings and other events throughout Surrey, and runs an online support group. It can also provide information about other local groups. Contact NAS Surrey Branch Officer Emma Whitfield: Email emma@mugsy.org or call 07423-435413.

The National Autistic Society (NAS) **Parent to Parent** Line is a confidential telephone support service for parents of a child with an ASD. It's a freephone number and the answer line is open 24 hrs a day. Volunteer parents access the line on their shift and ring callers back at a convenient time.
Tel: 0808-800-4106.

If you would prefer to talk to someone in person then in Surrey an organisation called **Face to Face** can put you in touch with a trained volunteer befriender who has been through the experience of having a child diagnosed with a disability. Tel: 01932-567131 (West) or 07947-254416 (East).

There are courses for parents of newly diagnosed children called **Earlybird** (pre-school children) or **Earlybird Plus** (children aged 5 - 8). These are courses developed by the NAS and run by Surrey County Council. For more information about them call 01737-737979.

6. What help am I entitled to?

You may qualify for financial help. Many children with autism and their carers are entitled to additional financial benefits and allowances. The main benefits for younger children and their carers are Disability Living Allowance (DLA) and Carers Allowance (CA).

These benefits are payable regardless of parental income and provide money to help offset the additional financial costs of having a child with ASD. DLA should be applied for first. Don't be put off by the size of the application form - you should be able to get help filling it in from your local Carers Support worker, Citizens Advice Bureau, social worker etc. (Your local Carers Support office number will be in the phone book, or find it on www.carersnet.org.uk.) Once obtained you may be entitled to CA and claiming this is a much simpler process. You should consider claiming these benefits as soon as possible as there is no back-dating of payment. Claim forms are available on the internet at www.dwp.gov.uk or from the local Citizens Advice Bureau, Children's Unit, or Hospital Social Services department. Or you can call 0845-712-3456 for a DLA Claim Pack and 0845-608-4321 for a CA form.

You may be able to get some help from your local Social Services office. They are required under law to have the main responsibility for providing support for children with disabilities and their carers. This support may be arranged by Social Services and could involve liaising with other authorities such as health or education. Social Services are obliged to assess any person who appears to be in need of services, and will decide what help, if any, they can provide according to the level of need determined following this assessment. Carers are also entitled to a separate assessment of their needs if they provide 'a substantial amount of care on a regular basis'. Start by contacting your local Social Services department (the number will be in the phone book).

The kind of help that Social Services may offer is short breaks (giving you a few hours respite from caring for your child); advice and counselling; childminding and playschemes. However, Social Services departments have limited resources and will not be able to give help to all those who request it.

Your child should meet the criteria to go on Surrey's Children's Disability Register, which is used by Surrey Children's Service to plan services and to send information to parents of children with disabilities. For more details contact the Register Administrator on 020-8541-8792.

7. What can I do to help my child?

You know more about your own child than anyone else, especially when it comes to the question of his or her particular problems, likes and dislikes. As with all children, a child with autism is a unique individual and you, as the parent or carer, are the expert.

Education is perhaps the most important issue facing parents, with so many crucial decisions to make. What kind of school will be best for my child - mainstream or special school? What extra help will be provided? Often the local paediatrician or psychologist will contact your local education authority (LEA), or your child's school, on your behalf. This is useful as it can save time in getting the authorities involved in your child's education. Otherwise it will be necessary to contact the Special Educational Needs department of your local authority. The number will be in your phone book. The local Educational Psychologist may then visit your child to assess his or her needs.

Outreach Teachers from special schools for children with ASDs can support pupils in mainstream schools, and offer some family support. They also run the **Earlybird** and **Earlybird Plus** courses, in which parents of children with ASDs learn how to help their child. The **Portage** service offers a similar programme for children with all kinds of learning or developmental difficulty. For information on Earlybird and Portage contact the co-ordinator on 01737-737979. For outreach in primary schools call Freemantles School, 01483-545680 (West Surrey) or Linden Bridge School, 020-8330-3009 (East Surrey). For information about secondary schools outreach call The Abbey School 01252-725059 (West Surrey) or West Hill School 01372-814714 (East Surrey).

Some children may require a '**Statement of Special Educational Needs**' - a legal document that specifies the extra provision that your child will receive from the LEA and other agencies such as the NHS. However, it is important to note that it is not necessary to have a Statement in order for your child to receive additional support. You can find out more about the Special Educational Needs (SEN) process from Surrey's **Partnership**

with Parents service. Tel: 01737-737300. Advice on education matters is also available from the NAS Education Rights Service on 0808-800-4102.

The number of **therapies** available to children with autism has increased considerably during the past 10 years or so. In addition to speech and language therapy or occupational therapy there are different educational approaches; special diets; medication; homeopathic or complementary medicine; sensory, music or art therapies; auditory stimulation, and more. Many make great claims as to their effect, but it is important to remember that many of the approaches are not widely accepted by professionals; most involve some financial outlay and there is no guarantee of success. However it is clear that some children, particularly those of a young age, do benefit from some of these approaches, so it may be worth investigating therapies in order to decide for yourself whether a particular approach might be suitable for your child. Further information about the various therapies available can be obtained from the NAS Helpline tel: 0808-800-4104.

One more thing....

.... you are entitled to seek a second opinion about your child's diagnosis. It is important that your child is correctly diagnosed as early as possible, because accessing appropriate provision (education etc.) is generally much easier with a firm and accurate diagnosis. Sometimes there may be difficulties in getting a firm diagnosis. This might be due to your child's young age and apparently subtle difficulties, or the doctor's inexperience with ASD's, or to a preference to adopt a 'wait and see' approach. If you are in any doubt about the diagnosis (or lack of it) then it may be appropriate to ask for a second opinion. Your G.P. can make a second opinion but if possible discuss it with your child's Consultant first. The Consultant will be able to discuss the 'pros and cons' and best timing of a referral as well as the most appropriate second opinion for your child.

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USEFUL CONTACTS

The National Autistic Society

393 City Road, London EC1V 1NE.
Telephone 0207-833-2299.
Autism Helpline 0808-800-4104.
Email: autismhelpline@nas.org.uk.
Website: <http://www.autism.org.uk/>
The UK's main charity for autistic spectrum disorders. Provides information, advice, advocacy, publications etc.

The National Autistic Society (Surrey Branch)

Branch officer: Emma Whitfield.
Tel: 07423-435413

Email: emma@mugsy.org

Website: <http://www.mugsy.org/>

Support through meetings for parents and activities for the whole family. There is also an email support group. The website includes local information and sound recordings of talks from experts in ASDs. The branch can also give contact details of other local support groups.

The NAS Education Rights Service is a scheme that aims to offer advice and support on education matters. Tel: 0808-800-4102. You will be asked to leave brief details and a volunteer will contact you afterwards.

The NAS Parent to Parent line

Confidential telephone support. Leave a message on the answer line at any time and a parent will call you back at a convenient time.
0808-800-4106

Autism Outreach West Surrey: for primary schools contact Freemantles School, Smarts Heath Rd, Mayford Green, Woking. GU22 0AN Tel: 01483-545680. For secondary schools contact The Abbey School, Menin Way, Farnham, GU9 8DY Tel: 01252-725059. East Surrey: for primaries contact Linden Bridge School, Grafton Road, Worcester Park. KT4 4JW Tel: 020-8330-3009. For secondaries contact West Hill School, Kingston Rd., Leatherhead. KT22 7PW Tel: 01372-814710.

Carers Support Surrey Go to:

www.carersnet.org.uk/localsupport/carermapping.html
for contact details of your local team.

Carers National Helpline offers advice about carers assessment, benefits and general information about care issues. 0808 808 7777 (Weds & Thurs 10-12, 2-4pm) Carers UK website: www.carersuk.org

Disability Living Allowance or Carers Allowance claim packs

For a DLA claim pack call 08457-123456
For a CA claim form call 0845-608-4321.
You can also get information and claim forms for these and other benefits online at <http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Caringforsooneone/index.htm>
See the NAS website at <http://www.autism.org.uk/> for information about claiming DLA and other benefits.

Earlybird, Earlybird Plus and Portage - Surrey

Call 01737-737979

Face to Face West Surrey: c/o

White Lodge Centre, Holloway Hill, Chertsey.
KT16 0AE Tel: 01932-567131

East Surrey: c/o YMCA, Princes Road, Redhill
RH1 6JJ Tel: 01737-779979

Website: <http://www.scope.org.uk/face2face>

Partnership with Parents - Surrey

Noke Drive, Redhill. RH1 4AX

Tel: 01737-737300 Email: pwps@surreycc.gov.uk

Website: <http://www.pwpsurrey.org/>

The Independent Panel for Special Education Advice (IPSEA) offers advice on special education needs issues.

Advice line 0800-018-4016

Website: <http://www.ipsea.org.uk/>

The Advisory Centre For Education (ACE) offers information and advice on all aspects of the maintained education service.

Advice line: 0808-800-5793

Website: <http://www.ace-ed.org.uk/>

SOS SEN is a small local charity offering information and advice on special educational needs issues.

Helpline: 020-8538-3731

Website: <http://www.sossen.org.uk/>

OTHER USEFUL INTERNET RESOURCES

The Autism Services Directory is building up a database of information on services of all kinds for all ages across the UK.

<http://www.autism.org.uk/directory>

Research Autism is building a database of interventions. <http://www.researchautism.net>

Do 2 Learn is an American website with a lot of free resources to help children with disabilities, including picture cards for communication.
www.do2learn.com

LOCAL PROFESSIONALS

You may come into contact with a number of different professionals during and after the diagnosis of your child. Here is a brief guide to what some of them do.

Paediatricians are doctors who are experts in the health and development of children. They assess, diagnose and treat children with developmental disorders, including ASD.

Child psychiatrists are doctors who are experts in understanding how developmental disorders can affect children's behaviour, emotional adjustment and social relationships.

Clinical Child Psychologists are experts in the development of learning, behaviour, emotional adjustment and social relationships. They provide assessment and counselling for developmental and behaviour problems.

Speech and language therapists (SaLTs for short) are experts in the development of language and communication. They can help to promote language and communication in people with developmental disabilities, including autistic spectrum disorders.

The Children with Learning Disabilities team is a group of professionals including nurses, psychologists and psychiatrists. They provide advice and support on a range of practical issues affecting children with learning disabilities or developmental disorders.

Occupational Therapists (OTs) are experts in understanding how developmental disorders can cause difficulties with senses and movement. OTs give practical advice to parents and carers about how to reduce every day problems faced by people with developmental disabilities such as ASD.

Dieticians provide advice, information and teaching on nutrition and diets, including modified diets for those who require them.

The Special Care Dental Service welcomes children with special needs and offers treatment and preventative advice on diet, tooth brushing and fluoride supplements.

Educational Psychologists will have worked as a teacher and then undertaken additional training in how children and young people learn and develop. An EP provides practical advice to schools and others on interventions.

LEA Case officers are administrators who act as a point of contact within the local education authority for information regarding a pupil with special educational needs. They liaise closely with other agencies, such as Health Trusts and Social Services.

Common abbreviations

ABA - Applied Behavioural Analysis

ADHD - Attention Deficit Hyperactivity Disorder

AS - Asperger Syndrome

ASD - Autistic Spectrum Disorder

CA - Carers Allowance

CAMHS – Child & Adolescent Mental Health Service

DLA - Disability Living Allowance

EP - Educational Psychologist

EPS - Educational Psychology Service

HFA - High Functioning Autism

IEP - Individual Education Plan

LEA - Local Education Authority

NAS - National Autistic Society

PECS - Picture Exchange Communication System

SA/ SAP School Action / School Action Plus

SaLT - Speech and Language Therapy

SCS - Surrey Childrens Service

SEN - Special Educational Needs

SENCO – Special Educational Needs Co-ordinator

SEND – Special Educational Needs &

Disability panel (formerly Tribunal)

TEACCH - Treatment and Education of Autistic & related Communication handicapped Children - an education method for children with autism.

Lovaas, Options, Son-Rise, Higashi - forms of intervention programmes for autism

Social stories - method of teaching social situations

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Leisure activities

NAS clubs

Activities for children and young people with autistic spectrum disorders - see <http://www.mugsy.org/nasservices.pdf> or call Kate Nixon on 07909-930086

Disability Challengers

Activities for disabled children and young people in Guildford, Farnham, Epsom, Dorking, Leatherhead, Oxted, Caterham.
Website: www.disability-challengers.org
Tel: 01483 579390 Leisure Development Project 01483 230930
Email: information@disability-challengers.org

Link Leisure

Activities for children and adults with learning disabilities in Woking and Surrey Heath.
Website: <http://www.linkleisure.org.uk/>
Tel: 01483-770037
Email: LINK@leisure-woking.fsnet.co.uk

YMCA Reigate & Redhill

Leisure opportunities for disabled children and young people in Redhill.
Website: <http://www.ymcarehill.com/>
Tel: 01737-779979
Email: admin@ymcarehill.com

White Lodge Centre

Activities for disabled children and young people in Runnymede, Spelthorne & Elmbridge.
Website: www.whitelodgecentre.co.uk
Tel: 01932-567131
Email: sbrooker@whitelodgecentre.co.uk

Family Information Service

Surrey County Council service providing information, advice and assistance to parents of children and young people aged 0 – 19 (or 25 for those with special needs.)
Website: www.surreycc.gov.uk/fis
Tel: 0300 200 1004
Email: <http://www.surreycc.gov.uk/fis>

Cinema Exhibitors' Association Card

This national card entitles the holder to one free ticket for a person accompanying them to the cinema. To be able to apply, the cardholder must either be in receipt of disability living allowance or be a registered blind person. The card costs £5.50 (at Dec 2010) and is valid for 1 years.
Website: <http://www.ceacard.co.uk/>
Tel: 0151 348 8020.

Special needs arrangements at leisure facilities

Many leisure facilities, including Chessington, Thorpe Park and Legoland, have discounts or special arrangements for people with disabilities. This can include being allowed to go on rides without standing in queues, which is a particular problem for our children. Check with the venue in advance what they offer and what proof of disability they require.

Family Fund Grants

The Family Fund provides grants to families with disabled children. The Fund will consider any request on its merits but does have specific criteria about claiming. See <http://www.familyfund.org.uk/>

Radar Keys for disabled toilets

The National Key Scheme offers independent access by disabled people to around 7,000 locked public toilets around the country. - price £3.50 including postage (correct at May 2010) To order see the RADAR website: <http://www.radar-shop.org.uk/>