

After diagnosis..... “WHAT HAPPENS NOW?”

*A guide for parents whose child has recently been diagnosed
with an Autism Spectrum Disorder*

If you have recently found out that your child has an Autism Spectrum Disorder (ASD), you may be feeling overwhelmed. Lots of questions will probably 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 to feel this way - even if you suspected that your child had an ASD, it may still be upsetting to have it confirmed. 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. This document covers some of the first questions you may have and includes information about:

- 1. What is an autism spectrum disorder?**
- 2. What caused it?**
- 3. Is there a cure?**
- 4. What are the long-term prospects?**
- 5. Is there someone I can talk to about all this?**
- 6. What help am I entitled to?**
- 7. How can I help my child?**

In this leaflet we will try to answer those questions, and give you details of organisations which might be able to help.

First there are two points we would like to stress:

1. It's not your fault!

Autism 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 an estimated 700,000 people who are on the autism 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 people with ASDs face, and many more professionals specialise in supporting children and adults with ASDs.

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

Autism spectrum disorders including Autism and Asperger Syndrome are lifelong developmental disability that affects how a person communicates with, and relates to, other people and the world 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 'Autism Spectrum Disorder'. 'Asperger Syndrome' is generally applied to somebody at the more able end of the autism 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 autism spectrum. 'High-functioning autism' is another term used to describe some people at the more able end of the spectrum.

Autism usually becomes apparent 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 causes of autism are still being investigated and the NAS supports a number of research projects. 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?

Autism 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.

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 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. A lot of progress has been made over the past 20 years in understanding ASDs - 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 and may say things like, "She's just a bit quiet - she'll catch up" or "You just need to be firm with him".

Sometimes it is hard for partners or relatives who are not the day-to-day carer of a child with ASD to understand 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**, such as the groups around Surrey run by parent volunteers from the NAS Surrey Branch. 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 support group meetings, talks and events throughout Surrey, as well as running an online support group. It can also provide information about other local groups. **For details of your nearest meeting, download our latest newsletter from www.nassurreybranch.org. You can also contact us via email at info@nassurreybranch.org or call 07423-435413 (answerphone).**

The National Autistic Society (NAS) Parent to Parent Line is a confidential telephone support service for parents of a child with an ASD run by the national NAS. 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 01737 222859 (East).

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 benefit for under-16s is Disability Living Allowance (DLA). A new benefit called Personal Independence

Payments (PIP) has replaced DLA for over-16s from April 2013. Carers may be eligible for a Carers Allowance (CA).

These benefits are payable regardless of the household 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 you have DLA you may be entitled to a **Carers' Allowance**, which is simpler to claim.

You should consider claiming any benefits as soon as possible as payments cannot be backdated. Claim forms are available online <https://www.gov.uk/browse/benefits/disability> or from your local Surrey Hub, Children's Unit, or Hospital Social Services department. 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, although resources are limited and they will not be able to give help to all those who request it. 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 Surrey Social Services on 0300 200 1006.

The kind of help that Social Services may offer is short breaks (giving you a few hours respite from caring for your child from time to time); advice and counselling; childminding and playschemes.

If your child has a diagnosis of an ASD, they 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. How can I 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 their parent or carer, are the expert.

Parent Programmes

Outreach Teachers also run **EarlyBird and Cygnet** programmes, which are designed to help parents of children with ASDs to learn how to best help their child. **EarlyBird** courses usually for one day a week over ten weeks and are for parents of pre-school children. Once you have registered, you will be invited to an information session before the course starts. **Cygnet** programmes are for families with children aged 5 up to 18. To register for either of these courses, contact training@linden-bridge.surrey.sch.uk Tel: 07747 595155.

Surrey's **Portage** service offers support families with children under 3 and a half with any learning or developmental difficulty. For details for your area contact 01737 737777.

Education is perhaps the most important issue facing parents, as there are 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? Sometimes your child's paediatrician or psychologist will contact the education department of your local authority (LA), 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 for your area of Surrey.

- **East Surrey Local Education Office:**
Consort House 5 – 7 Queensway,
Redhill, Surrey, RH1 1YB
Tel: 01737 737600
- **West Surrey Local Education Office**
Quadrant Court 35 Guildford Road
Woking Surrey GU22 7QQ
Tel: 01483 519900/01

The local Educational Psychologist may then visit your child to assess his or her needs.

Some children may require an **Education, Health and Care Plan (EHCP)**. These are legal documents that specify the extra educational provision that your child will receive from the Local Authority and other agencies such as the NHS (previously known as 'statements'). However, it is important to note that it is not necessary to have a Statement/EHCP for your child to receive additional support.

You can find out more about the Special Educational Needs (SEN) assessment process from SSIASS (Surrey SEND Independent Advice and Support Service - formerly Surrey Parent Partnership) www.surreyparentpartnership.org.uk Tel: 01737-737300.

Advice on education matters is also available from the NAS Education Rights Service on 0808-800-4102.

Outreach Teachers from special schools for children with ASDs can support pupils in mainstream schools. This should be arranged by your child's school.

Outreach to Primary Schools

West Surrey: Freemantles School, 01483-545680 Email: Vanessa Oldham

voldham@freemantles.surrey.sch.uk

East Surrey: Linden Bridge School, 020-8330-3009 training@linden-bridge.surrey.sch.uk

Outreach to Secondary schools

West Surrey: The Abbey School 01252-725059 Email Jill Currie:

jcurrie@abbey.surrey.sch.uk

East Surrey: West Hill School 01372-814714.

Therapies

Children who have speech, language or communication problems may benefit from speech and language therapy (SLT), and occupational therapy (OT) is often used to help children who have issues with postural stability and fine motor skills – such as holding a pen. These can be delivered by the NHS and are generally included in a child's Statement/EHCP or as part of their support in school.

The number of other therapies available to children with autism has increased

considerably during the past 10 years or so and include different educational approaches; special diets; medication; homeopathic or complementary medicine; sensory, music or art therapies; auditory stimulation and more. Many make great claims, but it is important to remember that many of the approaches are not widely accepted by professionals; most involve financial outlay and there is no guarantee of success. However it is clear that some children, particularly those of a young age, can benefit from some of these approaches, so it may be worth investigating and asking other parents for their experiences in order to decide for yourself whether an 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. Research Autism is building a database of interventions <http://www.researchautism.net>

One more thing....

You are entitled to seek a second opinion about your child's diagnosis should you so wish. It is important that your child is correctly diagnosed as early as possible, because accessing appropriate provision such as education or speech and language therapy 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 ASDs, or to a preference of a professional 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.

About the NAS Surrey Branch

The NAS Surrey Branch is a volunteer-run support group and offers a variety of local support groups, talks and activities for families with children and adults with autistic spectrum disorders (ASDs). It's free to join and we offer:

- Local support groups where parents can meet others with children with ASDs

- Evening talks by professionals each month in Redhill, Guildford and Woking on a range of subjects from education, benefits, therapies, employment and more.
- Family events such as ice skating, climbing, bowling and a children's Christmas party.
- Parents of Girls Group: meets in Woking and Guildford, plus social get-togethers with parents and girls.
- Dads' Group: a chance for fathers of children or adults with ASDs to meet in a member's home for a meal and a chat.
- Online support group: a moderated email group for members to share experiences and ask questions.
- Parents of Adults group: meets once a month in the evenings for informal get-togethers.
- Twitter feed [@NASSurreyBranch](#).

For details go to www.nassurreybranch.org

Useful Contacts

Parent Programmes

EarlyBird parent programmes are for parents of pre-school children with a diagnosis of ASD. They typically run over 10 weeks, for one (school length) day a week. These programmes are designed by the NAS and delivered by local autism schools on behalf of Surrey County Council.

Cygnets parent programmes are designed by Barnardos. They are for families with children aged 5 up to 18.

To register for either of these courses, contact training@linden-bridge.surrey.sch.uk Tel: 07747 595155.

Surrey's **Portage** service offers support families with children under 3 and a half with any learning or developmental difficulty. For details for your area contact 01737 737777.

Education

NAS Education Rights Service advice on education rights and entitlements
<http://www.autism.org.uk/advocacy> 0808-800-4102 (answerphone)

Surrey SEND Information, Advice and Support Service (SSIASS)

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

Consort House, 5-7 Queensway
Redhill RH1 1YB Helpline: 01737 737300
Admin: 01737 737301
Email: spp@surreycc.gov.uk

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/>

SOSISEN is a small local charity based in Hampton offering information and advice on special educational needs issues.
Helpline: 020-8538-3731
Website: <http://www.sossen.org.uk/>

Support & Information

NAS Surrey Branch

Parent to parent meetings, talks and activities all over Surrey. To join go to www.nassurreybranch.org or email info@nassurreybranch.org.

National Autistic Society

Advice on understanding behavior, communicating, education, welfare, schools
www.autism.org.uk
Helpline: 0808 8004104 (answerphone)
helpline@nas.org.uk

Surrey Local Offer

A portal run by Surrey County Council offering information about local activities, groups and support and services relevant to people with Special Educational Needs and Disabilities (SEND). <https://www.surreysendlo.co.uk/>

Carers Support Surrey

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

Carers National Helpline offers advice about carers assessments, benefits and general information about care issues. 0808 808 7777
Carers UK website: www.carersuk.org

Face to Face

Befriending service. West Surrey:

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>

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>

Resources

Do 2 Learn pictures

An American website with a lot of free resources to help children with disabilities, including picture cards for communication.
www.do2learn.com

Loan of weighted blankets and lap-pads. The NAS Surrey Branch has two blankets and two lap-pads available for members to borrow. Email emma@mugsy.org to request a loan (members only).

Benefits and Grants

Disability Living Allowance, Personal Independent Payments or Carers Allowance claim packs

For a Disability Living Allowance (DLA) or Personal Independence (PIP) claim pack call 08457-123456

For a Carers' Assessment (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/Caringsforsomeone/index.htm>

The **Get Wise** web site in Surrey

<https://getwisesurrey.org.uk/> contains useful information about all benefits and can offer help with completing forms.

Surrey Hubs

These hubs in Woking, Addlestone, Godalming, Camberley, Epsom, Redhill, Walton and Dorking provide drop-in benefits information. For details and opening times for your nearest hub, go to <http://www.thesurreyhubs.org.uk>

There is useful information about benefits on the NAS website at

www.autims.org.uk/benefits.

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/>

Leisure

NAS clubs

After-school and Youth Clubs for children and young people with autism spectrum disorders. These are run by the professionals at the NAS SE Resource Centre – email SEResourceCentres@nas.org.uk or tel 07909-930086 for details.

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 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

Autism-friendly film screenings

Run at Odeon, Cineworld, Showcase and Vue cinemas. For details sign up to the newsletter <http://www.dimensions-uk.org/support-services/autism-care/autism-friendly-screenings/>

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 year.

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.

Out and About

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/>

Who's Who

Some of the professionals you may meet:

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

CAMHS the Child & Adolescent Mental Health Service which often diagnoses older children with ASDs or those with complex conditions.

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

Clinical Child Psychologists - 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 or SLTs 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 autism 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 affect 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 usually have worked as teachers 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.

SEND Case officers are administrators who act as a point of contact within the local Surrey County Council 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 Terms and abbreviations

ABA - Applied Behavioural Analysis

ADHD - Attention Deficit Hyperactivity Disorder

AS - Asperger Syndrome. This is no longer given as a formal diagnosis as Aspergers is part of the Autism spectrum, although the term is still used.

ASD - Autism Spectrum Disorder (or ASC Autism Spectrum Condition)

CA - Carers Allowance

CAMHS – Child & Adolescent Mental Health Service (may diagnose an ASD)

DLA - Disability Living Allowance

Disability Register – Surrey’s list of children with disabilities in the county, used for planning purposes.

EHCP – Education, Health and Care Plan; the legal document that sets out the support a child receives from education and other agencies (**see Statement**)

EP - Educational Psychologist

EPS - Educational Psychology Service

HFA - High Functioning Autism

IEP - Individual Education Plan

LA - Local Authority

NAS - National Autistic Society

PECS - Picture Exchange Communication System. A system of communication used for children or adults with little or no language.

SaLT - Speech and Language Therapy

SCS - Surrey Children’s Service

SEN – Special Educational Needs

SEND - Special Educational Needs and/or Disability

SENCO – Special Educational Needs Co-ordinator. The person responsible for managing SEN delivery in a school.

Statement – a Statement of Special Educational Needs (SEN). These are being replaced by EHCPs in Surrey from 2014.

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

Social stories - method of teaching social situations