

ASPERGERS UNMASKED INFORMATION FOR PARENTS

SAFE is a support group for individuals and families working to:

- Raise awareness
- Provide support
- Share information
- Develop services

about Asperger Syndrome and High Functioning Autism

ASPERGERS UNMASKED has been written by parents, for parents, and aims to direct you towards the many sources of help which are available.

In the following pages we provide an introduction to AS and include resources and strategies – especially ways that other families have coped.

Understanding Asperger Syndrome is the first step to understanding your child.

There are thousands of children in Essex who have a condition known as Asperger Syndrome (AS). Asperger Syndrome is a form of autism. It is a life-long disability that affects how an individual makes sense of the world, processes information and relates to other people. This form of autism is often difficult to identify and a child could be any age from three upwards before the reason for their difficulty is diagnosed.

Parents say:

- “She doesn’t know how to make friends.”
- “We could see he was different from other children but people seemed to think it must be our fault. They blamed the parents.”
- They thought he was just a naughty boy, but now we know he didn’t understand what they wanted him to do.”

If you can relate to these comments, it may be that your child has AS.

If so, **ASPERGERS UNMASKED** is intended to give you information, support and advice.

Each child and family is different but many of the challenges they have faced will be similar to yours.



FIRST STEPS

“Once we knew what the problem was we could understand what he needed.”

Many of the parents who have spoken to SAFE say that finding out more about AS helped them to develop the confidence to get the best, most appropriate, help for their child and to be able to cope better at home.

NEXT STEPS

After reading **ASPERGERS UNMASKED** you may wish to obtain further information on specific topics. See inside for suggestions or email the SAFE Helpline – see page 7 for details.

COULD IT BE ASPERGER SYNDROME?

How will you know if your child's difficulties are caused by Asperger Syndrome (AS)?

A full assessment by an appropriately qualified medical expert will give you a diagnosis. However, there are a number of indicators that may suggest your child has AS.

Did your child:

- Fail to draw your attention to objects of interest, by pointing, at an early age?
- Develop language late and speak in a stilted and formal way, or use language earlier than most, often inappropriately and with little understanding of words or context?
- Fail to play with other children?

These and other signs may indicate your child has AS although girls may be less likely to exhibit typical Asperger characteristics.



WHAT IS ASPERGER SYNDROME?

Autism was first described in the 1940's. Kanner described what we now call "classic autism". Soon after, Hans Asperger wrote a study about German children with a particular form of autism. The children he described were of average or above average intelligence, often with fluent speech and language. But their social behaviour and rigid way of thinking were similar to the autistic children Kanner described. Asperger's work was not well known until the 1980's when it was translated by Lorna Wing. Since then, his ideas have been researched and developed to describe and explain the syndrome.

Autism is now thought of as a "spectrum" which includes AS at the high-functioning end. People on the spectrum share the same difficulties but are affected to varying degrees.

Did you know that more boys than girls have AS and other autistic conditions?

The ratio is 4 boys: 1 girl



"This (SAFE STUFF) club is special to me and every child that comes, it shows that they are not alone and can make friends that are the same as them rather than different. I don't know what I would do without SAFE."

KEY FEATURES OF ASPERGER SYNDROME

Social Communication & Language

Children with AS find it difficult to express themselves. Speech may not develop normally and even when it does, good verbal skills can mask a lack of understanding. For example, words are used inappropriately or taken literally, leading to confusion. The child may be overly precise in the use of “correct” words or names and their speech may be stilted and lacking in expression. Consequently, children with AS often have difficulty understanding jokes, metaphor and sarcasm.



Social Relationships

Friendships can be difficult to make and keep. Children with AS do not understand how to relate through conversation, play or shared interests. Turn taking and body language is not understood. Consequently, children with AS have difficulty knowing when to start and end, often one-sided conversations, and find the behaviour of other children confusing. Whilst they may want to make friends, children with AS lack the instincts and understanding to do what their peers do naturally.

Lack of Empathy and Social Imagination

Many parents of AS children say that their children are imaginative and creative – some are very musical or artistic. However, children with AS lack empathy and social imagination – they find it difficult to imagine alternative outcomes to a situation and find the world and the actions, thoughts and feelings of others, confusing and unpredictable. As a result, they may seek comfort in repetitive activities and routines.

Sensory Difficulties

A child with AS may have over active or underdeveloped reactions to one or more of the senses. For example bright lights, loud noises, overpowering smells or particular textures (food or material) may cause them problems. Children with AS may also lack spatial awareness - stand too close to people, appear clumsy or have difficulties with fine motor control such as tying shoe laces. Some children with AS may rock or spin to help with balance or alleviate stress.

WHAT DOES ASPERGER SYNDROME MEAN FOR MY CHILD?

AS will not affect your child’s intelligence but it will influence their ability to relate to their peers and learn in the classroom. Some ways of working will be easier than others. For instance, boys who prefer logical work may thrive in science and maths, whilst girls may excel in creative subjects. Children with AS often find the technical aspects of reading easy but comprehension, analysis and abstract reasoning can be a major difficulty. They may find organising themselves and the school day difficult and unpredictable changes in routine upsetting. These frustrations may lead to poor behaviour or “withdrawal” in the classroom.

Parents of children with AS discover that the inability of their children to make friends becomes increasingly problematic. Without the skills to know how to join a group and relate to others, children with AS can feel left out by their peers and may become lonely and unhappy.

Some children with AS have a gentle charm and an unusual but engaging personality, appreciated by discerning people. Others may be reluctant to engage with anybody, especially outside the family circle. There are also a number of children with AS who may be aggressive, demanding constant attention and refusing to comply with accepted rules of behaviour at home or school.

But remember, each child is different. Those with siblings sometimes seem to cope by “tagging along” as part of a group and copying others in order to belong. Others will be “loners”.



HELP AT SCHOOL – YOUR CHILD IN & OUT OF THE CLASSROOM

As a parent of an AS child, you know your child best. Use your knowledge to work with the school to ensure they meet your child’s needs. Here are a number of strategies that may help:

Make sure your child is:

- Given plenty of warning of any changes in routine, timetable or staff changes – reducing stress and poor behaviour;
- Seated near to the teacher but facing away from other children so they are not distracted;
- Given clear explanations of work to be done so they know what is expected of them.

Ensure teachers:

- Are aware of the particular needs of your child and have strategies/support in place;
- Differentiate lessons to meet their needs;
- Make sure your child has understood any instructions before going onto something else.

P.E., Games & Dance

Children with AS, who also have poor co-ordination (called Dyspraxia), may find that their clumsiness makes them vulnerable to teasing and bullying, especially if the teacher is not sensitive to their difficulties. They may also find it hard to participate in “team games” and be slow to get changed after activities. The use of “Velcro” trainers/shoes and extra time to change can help.



Break & Lunchtimes

These may be particularly difficult for the child with AS who has difficulty coping in large, noisy groups. They may be confused or repelled by boisterous behaviour and prefer to spend time alone. But solitary occupations such as walking round the edge of the playground, possibly talking to themselves or acting out some personal fantasy may attract teasing or bullying. Provision of a quiet refuge and supervision by an understanding adult is vital. Parents often say that this is a most valuable use of a Learning Support Assistant’s time.

“SAFE made me feel sane again – people there had similar problems with their young people and really understood what I was going through and that was so rejuvenating.”

Homework

Children with AS may refuse to do homework, at home, as “school work is done at school not at home”. One solution is to ensure they complete homework at school – some schools offer “homework clubs”; another is to tailor homework to the child’s special interests.

Your help and understanding will be vital for your child’s well being and will enable you to work with the school’s Special Educational Needs Co-ordinator (SENCO) in meeting your child’s needs.

HELP AT HOME WITH PROBLEM BEHAVIOUR

AS families report a range of problems that affect home life.

Routines

Children with AS often feel more comfortable when they follow a routine such as always walking the same route to school or eating the same meals on particular days. This can develop into unacceptably rigid behaviour which can cause friction within the family and may lead to frightening temper tantrums.

Obsessions

Obsessions and special interests dominate the AS child’s life such as the repetitive watching of videos, playing music and computer games. Whilst these obsessions provide them with support and comfort, their need to over indulge on their special subjects can easily annoy the rest of the family. Furthermore, some of these special interests such as trainspotting or collecting car numbers may attract derision, further isolating the child from their peers, especially as they enter teenage years when such interests are considered “uncool”.



Sometimes, an obsession can be channelled allowing the child with AS to become an expert in a subject, gaining their peers respect; this may also lead to a fruitful career.

Many children have food fads but, for the child with AS these are more intense and last longer. They may include where and when food or drink is bought, its shape, colour and texture and how it is prepared and where and how it is presented. Brands and packaging influence choice more than normal and the resulting diet may be unbalanced or inadequate for a growing child. They may also suffer from intolerances to gluten and lactose.

Other Problems

Some children with AS talk to themselves. They may also engage in “stims” (self-stimulatory behaviour) - they might flap, rub their hands repetitively, rock or blink their eyes rapidly.

Many people with AS are socially naïve. This vulnerability may result in them being taken advantage of. Their understanding of money may be deficient and their sense of direction faulty. If they also lack a sense of danger they may be prone to wandering off.

As yet, there is no cure for Asperger Syndrome but, with effort and support, you can develop strategies to manage these situations and improve your family’s quality of life.

WHAT IS SAFE?

Supporting Asperger Families in Essex

A parent support group formed in 1997, SAFE links families across Essex whose children have this condition. Hundreds of families have made contact and many find that talking to others who share similar experiences and feelings helps them cope.

SAFE also offers a valuable opportunity to exchange information on practical topics including how to claim benefits, obtain a statement of special educational need, how to access supported living and how to plan for the future.

SAFE works with education, health, mental health, carers' organisations and social care service departments to improve and develop services for children and adults with AS and their families in Essex.

- *"It's nice to be able to talk to other parents of children with Aspergers and to know that other people out there are going through what we are."*
- *"For us, the experience has been amazing. Finding out that there are other people in the same boat and exchanging experiences and tips is very comforting."*

You can attend regular parent meetings of SAFE support groups in the Essex and Southend areas.

DON'T FORGET . . .

If one member of the family has AS every member is affected. Brothers and sisters may become resentful if one of them gets "special allowances", or they can't do things as a family because of their AS sibling's unpredictable or embarrassing behaviour. Grandparents, uncles and aunts will also need to understand what AS involves.

The stress of managing difficult behaviour can cause problems between parents. Accepting the diagnosis may be difficult for some parents and children. Reading, talking to others or getting help from professionals will help.

Activities SAFE offers:

We have introduced a number of initiatives to help children and teenagers with AS to develop their social skills and form friendships:

- **SAFE STUFF** (Social Training Using Fun & Friendship) – an activity for children aged 7-12 which provides an opportunity for them to learn and practise social skills in a safe, creative and non-threatening environment in Saturday morning sessions across the county.
- **Youth Groups** - We run two youth groups for teenagers – one covering the south of the county; the other in the north. Both groups meet on a regular basis and members socialise and participate in activities such as going to the cinema and bowling. All our groups are supported by volunteer facilitators who help them learn valuable social and independence skills.
- **Social Skills Courses** - SAFE has successfully run a number of social skills courses for teenagers. We are in the process of developing "life skills" for teens: including cooking, shopping, making decisions and team work.
- **ASAP** (Asperger Syndrome Adults and Parents) – Once your child reaches the age of 17+, they can attend a separate group set up specifically to deal with issues particular to adults such as independent living, supported employment and training, social interaction and relationships, adult social care and mental health. Members can also get together socially and receive a monthly newsletter with further advice and information tailored for their needs.

With this ongoing support, our children can understand the very confusing world we live in and be happy. It is a joy to see them develop.

SAFE CONTACT NUMBERS

SAFE/ASAP Information – Email: info@safeessex.org.uk

SAFE Website – www.aspergers.org.uk

SAFE/ASAP – carolann.jackson@talk21.com • Tel: 01206 240931

SAFE Support Groups and Youth Group – www.aspergers.org.uk

WHERE TO GET MORE INFORMATION

Websites and advice lines

National Autistic Society

Website: www.autism.org.uk.

The NAS website and helpline (0808 800 4104) offers support and advice on a range of topics including benefits, employment, therapies and interventions.



The Education Rights Service Helpline:

Telephone: 0808 800 4102

Provides advice on educational provision, including assistance in obtaining a Statement of Special Educational Needs.

ACE (Advisory Centre for Education)

Website: www.ace-ed.org.uk • Telephone: 0800 800 5793

Offer free advice and support to parents on education and SEN issues including exclusion and bullying.

Families InFocus (Essex)

Website: www.familiesinfocusessex.org.uk • Telephone: 01245 353 575

Provides advice, information and support to families with children with disabilities and special needs.

IPSEA (Independent Panel for Special Education Advice)

Website: www.ipsea.org.uk • Telephone 0800 018 4016

Provide advice on the legal duties of LEA's towards children with SEN and provide free, independent advice on educational issues.

Network 81

Website: www.network81.org • Telephone 0845 077 4055

Is a network of parents working towards inclusive education for children with SEN.

Trained befrienders can support parents at meetings and through the assessment process.

OAASIS (Office for Advice Assistance Support and Information on Special Needs)

Website: www.oaasis.co.uk • Telephone: 0800 197 3907 • Email: oaasis@cambiangroup.com

SNAP (Special Needs and Parents)

Website: www.snapcharity.org • Telephone 01277 211 300

Is a Brentwood based charity providing advice and support to Essex families who have children with special needs and disabilities.



In Support of the Community

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