

ASPERGER ADULTS UNMASKED

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

Famous people thought to have had Asperger Syndrome . . .

Jane Austen
Bela Bartok
Ludwig van Beethoven
Charles Darwin
Thomas Edison
Albert Einstein
Edward Elgar
Bobby Fisher
Benjamin Franklin
Bill Gates
Carl Jung
Franz Kafka
Charles Rennie Mackintosh
Wolfgang Amadeus Mozart
Issac Newton
Friedrich Nietzsche
Gary Numan
Bertrand Russell
Eric Satie
George Bernard Shaw
Alan Turing
George Washington
Vincent Van Gogh
Virginia Woolf

And in fiction –

Dr Sheldon Cooper from the Big Bang Theory
Sherlock Holmes

Charity Number 1095075

DID YOU KNOW?

- The latest National Autistic Society prevalence figure indicates that there are over 5,000 adults with Asperger Syndrome (AS), most of whom are undiagnosed.
- The ratio is one female with AS to four males.
- The vast majority of people with AS have average to well above average IQs? Only approximately 5% have an accompanying learning disability.

“Once I got my diagnosis of Asperger Syndrome two years ago, my life started to make sense. Now I know why I was having so many problems, and I can at last start to find support” (Man aged 28)

People with AS perceive the world in a different way to others. They find the rest of us strange and baffling.

Why don't we say what we mean?

Why do we do so many things we don't mean?

Why do we often make trivial remarks which mean nothing at all?

Why do we tolerate such a confusion of sensations of light, sound, smell, touch and taste without getting to screaming pitch?

Why do we care about social hierarchies – why not treat everybody the same way?

Why do we have such complicated social relationships?

Why do we send and receive so many social signals to each other and how do we make sense of them?

Above all, why are we so illogical compared to people with Asperger Syndrome?*

Lorna Wing

“After my diagnosis of Asperger Syndrome, I felt a great sense of relief: I had a recognised medical condition and I wasn't mad, bad or sad!” (Woman aged 23)



This book was written by Nita Jackson, aged 18 years

THINK BACK TO WHEN YOU WERE A TEENAGER – OR EVEN YOUNGER . . .

Do the following sound familiar?

- Were you always getting into trouble? Told you were naughty or attention-seeking?
- Did you always feel “different”? Were you the brunt of teasing or bullying? Or did you bully others?
- Did you have difficulty making or keeping friends? Were you the one left on the sidelines?
- Were you always saying the wrong thing at the wrong time and didn’t understand why?
- Did you dislike change, alteration to routine, going to new places or meeting new people?
- Did you have a special interest which you talked about constantly and at inappropriate times?

A BRIEF OUTLINE

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 this lifelong syndrome. Autism is now thought of as a spectrum, which includes Asperger Syndrome (AS) at the high-functioning end. People of all ages are on this spectrum and share the same difficulties but can be affected to varying degrees.



Lucie Strong, applying fashion make-up for which she was trained

KEY FEATURES OF ASPERGER SYNDROME

Social Communication & Language

When you have AS you find it hard to express yourself. Your speech may not have developed normally when you were a child. Even if it did, good verbal skills can mask a lack of understanding. For example, words are used inappropriately or taken literally, leading to confusion. You may be overly precise in the use of “correct” words or names and your speech may be stilted and lacking in expression. You may have difficulty understanding jokes, metaphor and sarcasm.

Social Relationships

Friendships can be difficult to make and keep. Adults with AS can sometimes lack understanding of how to relate through conversation or shared interests. Turn taking and body language may not be fully understood. You may find it difficult or confusing to interpret facial expressions, tone of voice and body language in others. Consequently, you may have difficulty knowing when to start and end conversations.

Lack of Empathy and Social Imagination

When you have AS you may lack insight and only see the world from your viewpoint – you may only want to talk about your own special interests. You could find it difficult to imagine alternative outcomes to a situation and find the world, people's actions, their thoughts and feelings confusing and unpredictable. This affects social relationships, your perception of the world and the way you continue to learn. As a result, you may seek comfort in repetitive activities and routines and may have a special interest or hobby that takes up a great deal of your time.

Sensory Difficulties

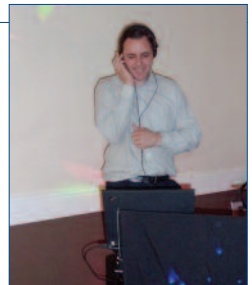
An adult with AS may have overactive or underdeveloped reactions to one or more of the senses. For example bright lights, loud noises, overpowering smells or particular textures (food or material) may cause you problems. You may also lack spatial awareness - stand too close to people, appear clumsy or have difficulties with fine motor control. At times of stress you may rock or spin to help with balance or alleviate stress.

WHAT DOES ASPERGER SYNDROME MEAN FOR ME?

You may have problems with these situations . . .

Employment

“The Disability Employment Adviser (DEA) sent her to an interview as a receptionist at a hotel where she was expected to make eye contact and have a friendly, welcoming manner – all the things people with AS find hard to do.” *(Mother of 20 year old woman)*



Simon DJ'ing with NightFlight

Independent Living

“He cannot live independently without considerable daily support. He can't cook – he hasn't any idea how to manage money or keep a flat, or himself, safe and clean despite his high IQ.” *(Mother of 26 year old man)*

Further/Higher Education

“At college I had great difficulty in organising myself, getting from A to B and concentrating on my studies. I also found it hard to get on with the other students.” *(Man aged 30)*

Relationships

“All he wants is a girlfriend. He gets so angry when he sees his non-autistic peers out having fun when he is always left out.” *(Mother of 31 year old man)*

Social and Leisure Activities

“Because she finds it so difficult to socialise and join in, she spends all her time at home with us. She is becoming very depressed.” *(Mother of 30 year old woman)*

INTERESTING FACTS

It is difficult to know exactly how many people have autism. In 2008 research suggested that 1 in 100 people have autism. However, as some with undiagnosed AS might have been missed from the research this figure should be regarded as a MINIMUM figure. Indeed more recent work suggests that prevalence rates could be considerably higher.

Females are less likely to be picked up as having AS because current diagnostic criteria is male centric and females are less likely to exhibit typical AS characteristics.

The annual cost of autistic conditions in the UK is in the region of £27 billion. The lifetime cost for someone with ASD is estimated at approximately £2.9 million to £4.7 million depending on whether they also have an intellectual disability.

65% of people with AS suffer some form of depression and anxiety. Ghaziuddin et al (1998) found that 65 per cent of their sample of patients with Asperger syndrome presented with symptoms of psychiatric disorder.

... BUT LOOK WHAT YOU CAN DO!!



"Although she needs my daily support, she is now living in her own flat and is slowly learning how to manage her own affairs. It will take time, but I'm sure she will get there in the end." *(Mother of 24 year old woman)*

"After several bad starts, he now has a job working in a small company for an employer who understands AS. He feels supported and is happy." *(Mother of 28 year old man)*

"I didn't know my husband had AS until our son was diagnosed. The marriage worked as I was the 'front man'. He has many qualities and his ability to focus on some problems is phenomenal" *(Wife of 40 year old man)*

"He found lots of Asperger chat rooms on the internet, and has now made virtual friends from all over the world who share the same interests. He also joined an Asperger social club where he can meet others like himself, as well as their peers who come along to support them." *(Mother of 24 year old)*

"At college he was able to access a daily mentor. They found him a buddy who helps him socially and the teaching staff have now all had Asperger training. He is now much more motivated and positive about his future." *(Mother of 21 year old man)*



"We are marginalised in society. We are seen as weirdos and so when we meet these others with the same problems then we are not weirdos anymore. We feel a collective consciousness."



WHAT IS SAFE?

A parent support group formed in 1997, SAFE links families across Essex whose relatives (of all ages) have this condition. Hundreds of people have made contact and many find that talking to others with AS and their families, 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, how to access supported/independent living, how to get into the job market and how to plan for the future.

SAFE works with employment, 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.

WHAT SAFE CAN PROVIDE

SAFE continues to develop a range of support activities for adults and children with AS and their families. We have two branches for adults (17+) and their families: Asperger Syndrome Adults and Parents (ASAP) based in Chelmsford and in Southend on Sea.

At present we offer:

- ASAP monthly support group meetings
- Monthly newsletters
- ASAP socials for adults and their families
- Specialist training courses for adults with AS

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 North & South Support Groups and Youth Groups – www.aspergers.org.uk

“And it’s just about being a champion for autism and saying that it needn’t be the end of everything and it needn’t be unmanageable and chaotic. I’ve got the diagnosis . . . and so I just tell them that because really it’s just being able to have this self-worth and responsibility that grows you as a person.”

WHAT SUPPORT COULD BE AVAILABLE TO ME?

SAFE/ASAP (Asperger Syndrome Adults and Parents)

SAFE’s support group for 17+ and their families.

Contact: Carolann Jackson on 01206 240931 • Email: carolann.jackson@talk21.com

National Autistic Society -

Website: www.autism.org.uk • Help Line: 0808 800 4104

Autism Anglia -

Website: www.autism-anglia.org.uk/ • Tel: 01206 577678

Community Care Assessments for Adults

To assess your needs call your local Social Care Services department.

Carers’ Assessments

To assess parents’/ carers’ needs call your local Social Services department

Advocacy (Essex) Services -

Website: www.advocacyessex.co.uk/about_aes.htm • Tel: 01245 382 838

Mental Health Services –

Contact your local Community Mental Health Team

Help With Employment –

Disability Employment Advisor at your local job centre

NAS Prospects - Website: www.autism.org.uk/our-services/employment-support/jobseekers.aspx

Transitions Pathway Team –

Provide support for all young people with a statement of educational need and “plan their journey from childhood to adulthood”

Website: www.essex.gov.uk/Health-Social-Care/Care-Children/transition-adulthood/Pages/Default.aspx

SAFE -

Email: info@safeessex.org.uk • Website: 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.

Autism Anglia –

Website: www.autism-anglia.org.uk/default.htm.

Tel: 01206 577678 • Email: info@autism-anglia.org.uk

Aspires –

Website: www.aspires-relationships.com/

Help with benefits and finding work:

Prospects –

A range of courses offered by the NAS to support people with autism into employment - email: www.autism.org.uk/our-services/employment-support/jobseekers.aspx

Disability Rights UK –

Provides information on education, work and independent living

Website: www.disabilityrightsuk.org

General enquiries: enquiries@disabilityrightsuk.org

Disabled students helpline: skill4disabledstudents@disabilityrightsuk.org

Independent Living advice helpline: independentliving@disabilityrightsuk.org

Disability benefit enquiry line: Website: www.direct.gov.uk/en/dl1/directories/dg_10011169 for help claiming disability living allowance and attendance allowance

Disability Essex –

Website: www.disabilityessex.org/

Provide advice and training to enable people with any disability to control their own lives and enjoy to the full the opportunities which society, the economy and the environment offer.

Chat rooms for adults with Asperger Syndrome:

www.aspievillage.org.uk – a forum for adults with Asperger syndrome

www.asd-forum.org.uk/forum/ – Forum for all those affected by autistic spectrum conditions

OLYMPUS

In Support of the Community

Asperger Adults Unmasked layout and printing by Olympus KeyMed