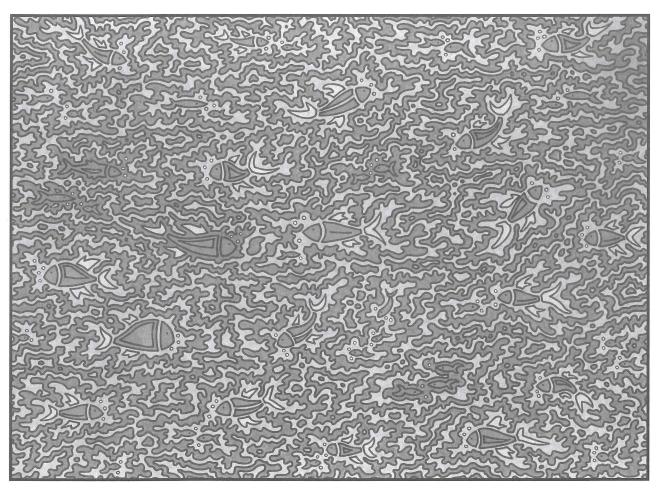
Produced by and for people with Asperger syndrome ASPEC GET Edition 36 October 2003



Fish in water - Peter Myers 2003







Asperger United is a self-help newsletter run by and for people with Asperger syndrome. The newsletter aims to put people with the condition in touch with each other and to share information so that they can lead more independent lives.

Asperger United is free to people in the UK with a diagnosis of Asperger syndrome. We ask for a contribution of £6 per year from overseas readers and £10 from professionals and institutions to cover postage costs.

Editor John Joyce

Additional support The National Autistic Society's Publications Department

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Subscribing to Asperger United

Tel: 020 7903 3541 Fax: 020 7903 3767

Email: asp.utd@nas.org.uk

All we need is your name and address and we will add you to the mailing list – free of charge to people with a diagnosis!

Thank you to George Cox who kindly produced the illustrations included in the Pen Pal Network section. Thank you to Graeme Lawson for producing the AU logo.

Please note that the views expressed in Asperger United are not necessarily those of the editor, The National Autistic Society or those involved in the publication of the newsletter.

Contributions for the next isssue should reach us by 1 November 03

Asperger United was founded in 1993 by Pamela Yates and Patricia Howlin, in association with the Maudsley Hospital, and Mark Bebbington and Judy Lynch of The National Autistic Society.

This was in response to a recognised dearth of services for people with Asperger syndrome and the potential for self help and networking as a means of support for this group.

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds and the current editor, John Joyce.

Pamela Yates provided support and advice to the editors until the publication was handed over to the NAS in 2000.

The name Asperger United was chosen by the group of original readers as the most 'appropriate name' for the publication. This was suggested by Anna Cohen.

Dear readers

Welcome to the latest edition of your newsletter. Hope you have all enjoyed the summer and are ready for the autumn.

I have had a lovely summer. Got temporarily promoted at work and made another pilgrimage to Lourdes. I have completed my booking for the European Autism Congress in Lisbon. I also attended a family event in July. I will give you clues to lead you to the location.

Due to the amount of contributions we've had in this time, I've been unable to add my personal comments at the end of each article, as I usually try to do. So can I just say a big thank you to all contributors and please continue to send your work in.

Best wishes from

JOHN JOYCE

Guess where I went in July

I travelled on a ferry called Ulysses. My destination was the island on the far west of Europe where my family gathered for my parents' diamond jubilee.

Arriving in the capital I took a train to the westernmost county where I met with my brothers, sisters, nephews and nieces and locally based relatives.

I stayed in a house halfway up a hill overlooking a great lake. It is a large house whose owner is a US resident. My younger brother and his family lived in another house called 'Teach Bhar Atlieve' farther up the hill.

We had a religious celebration and a small party. I had two walks in the countryside.

Can you guess which country?



in this edition

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Dear AU

Like Gunilla Gerland (author of *A Real Person*) and many of us, I was bullied and misunderstood at school, culminating in a suicide attempt at 17. I was also good at languages and at 18 won a place at Oxford University (through the back door it must be admitted) to read French and German language and literature. This was even though I had only achieved a grade 5 (E) and grade 4 (D) in English language and English literature GCE 'O' levels respectively.

The techniques I had used to get to Oxford (rote learning vocabulary and phrases and memorising stock literature essay answers) did not work when I eventually got there. I was unable to think in the ways required or argue logically or indeed read 800 page French novels even in translation – little wonder as I hated reading novels anyway. Got the bottom mark in the whole of the university in my 'prelim' exams and dropped out at the end of the first year. Two things I did learn at Oxford were drinking and punting.

I then went to an Occupational Guidance Counsellor to determine which job might be suitable for me. As a result of a questionnaire and also a Monty Python sketch, where a chartered accountant was advised to

transfer to lion taming via banking – 'a real man's world', I joined Lloyds bank 30/11/70.

Although I got my banking diploma (ACIB) I couldn't 'team-work' or follow the normal promotional path, and when promoted into front line role, at a time of great change after some 15 years of doing my technical one-man job in the background, I failed miserably. I was unable to make the necessary relationships with staff or customers. I had no alternative but to take redundancy on 31/3/91. I then did an Open University degree in banking related subjects.

I have been unable to fit in anywhere else, either in lower paid clerical employment, or in the worst jobs – cleaning loos at 6am etc. I ended up cleaning for some six years. Not surprising that I've had no friends for most of my life.

In my 20s I was drinking 100 units of alcohol per week on a regular basis; at 24 I was thrown out by my parents; this also followed years of anorexia and bulimia.

I was fortunate to have met my wife when I was 29 and she 20 (she thought I was about 24), when drunk after a beer festival. Despite a few minor problems we're still together and have 2 children, 22 and 19. Our

younger child certainly has some Asperger traits but is coping. My wife is very tolerant.

By the time I was 50 I had ruled out all possibilities of explaining the way I was – e.g. only child, natural introvert, badly brought up, spoilt brat etc. – except that I might be an 'Aspie'. By this time I had read an article about it in a newspaper, decided to get myself diagnosed and was duly declared a 'textbook case' in March 2002.

I'm convinced I will never work again (I am now 52). I spend much of my time walking, cycling and swimming (sometimes alone, sometimes with my wife). I'm currently in a battle with my exemployer Lloyds Bank (now Lloyds TSB), seeking an ill health pension, having already qualified for Disability Living Allowance (DLA).

When I was diagnosed I was told, 'Don't expect anything', and certainly as far as employment is concerned, this is true. I believe it is absolutely impossible for me to fit in anywhere. Even in so called one-man jobs you still have to get on with various people day after day, which I just cannot do. My wife is the only person (apart from psychologists) who understands me.

J. Huitson

Dear Asperger United readers

I am in the process of setting up an art and poetry exhibition centre. MERGE, as I hope it will be known, will offer a platform for people with autism, the homeless and the disadvantaged artist to work alongside the established and successful artist – with a chance to exhibit their work and perhaps sell and begin a career leading to independence.

I have a son with autism, I work with The National Autistic Society as a volunteer and I am studying autism at the University of Birmingham. I have also worked with children with autism at a school in London.

If you would like to get involved wth MERGE please email me at csphalden@hotmail.com or you can contact me via *Asperger United* (contact details are on page 2). All correspondence sent or emailed to *Asperger United* will be passed on.

Looking forward to hearing from you - Caroline Halden

Approaching 30 and more settled in myself

Hello everyone! Some of you will remember my name from past articles, letters and poems in AU. I've been wanting to write something for you all for a while, so here goes ...

I'm Joanna, I'm 29 and I have HFA. I live in supported housing in a shared house in Cumbria. Due to my ethics and allergies I have a severely restricted diet, which takes a lot of time and effort to cater for.

My childhood and 20s have been turbulent to say the least. I was an 'outsider' at school, left college due to social pressures and eventually 'joined' the mental health system as a service user in 1992 at the age of 18.

At 23 I cut out dairy produce from my diet for ethical reasons, and became interested in developing social skills. A coincidence? Unlikely. I started watching carefully how other people had conversations and interacted at a mental health drop-in centre I attended. I had my own flat, three cats and a dog for company. I spent up to four months a year on a psychiatric unit as an inpatient and deliberately injured myself, regularly needing medical intervention.

When I was 26 I had my most severe anorexic episode and realised I could no longer manage living alone. The outreach worker at the drop-in centre helped me get into supported housing. The hardest thing I ever did was rehoming my cats and dog. I cried for months about doing that to them. I still have photos of them standing by my bed. (I have no photos on display of my family and friends, though there is one of a friend's rabbits).

Last year I noticed a new shop in my area selling crystals and alternative spiritual/health products. On impulse I inquired about working there. On my disability benefits I can earn £20 per week. I was amazed, thrilled and stunned when I was asked to come for an interview and then taken on as

a member of staff. It's surprising how much difference working four hours a week makes to my self-esteem. I no longer have to lie when someone asks what I do (I used to say I was a psychology student - isn't everyone on the autistic spectrum!). I love the work and have gained confidence. I'm even finding it easier to take phone calls at work, which I found really difficult at first. I like the customers, and the good atmosphere in the shop means people who come in are usually pleasant and accepting. And I get paid to spend several hours a week surrounded by crystals - a dream come true!

I'm proud of myself for finding and securing a job all by myself, and I'm lucky that my employer is very accepting of me and supportive. I was honest with her about my difficulties and she gave me a chance, which has more than paid off all round.

So what else do I do? Every other month I stay overnight in London and attend an Energy Resources (green issues) working group within my landlord/housing association. I have something to offer to the group (knowledge, experience and a tenant's perspective) and I'm happy to put in the time and effort.

A new mental health service called Assertive Outreach started up locally. I became involved by helping with interviewing for a team member and my ongoing input helps keep the service friendly and accessible to service users.

Another local woman and I are doing our best on starting up a group for adults with AS/HFA in South Cumbria. This goes in fits and starts as my friend and colleague has a lot

of illness and stress, but we've had a few meetings so far and have about five or six regular members as well as some who don't want to attend meetings.

Less regularly, but as importantly, I have the confidence to travel and to go on holiday. This year I met up with a long-term pen friend for the first time and we've become better friends yet. She has recently visited here too. It was a big deal for both of us to meet up, dealing with our autism/exposure anxiety and social avoidance.

Generally, as I approach my 30th birthday in less than six months time I feel that my life has changed hugely and for the better. I still have problems, get anxious and depressed and self injure occasionally. But I have reasons to pick myself up and keep going. When I make a bad mistake or have an awkward social experience it's easier to let it go, even laugh ironically. I have positive people in my life who mean more to me than they know, and I know I am positive for others.

My message for all AU readers – for all with AS/autism – is: it can get better and easier. Not 'easy' but less hard and more positive. Looking at my case from the outside it would be easy to focus on the negative things – I still hurt myself, get depressed and have problems with eating properly. My diet is restrictive and time consuming. My back pain restricts my physical activities. But I'm a happier person.

I'm still autistic and wouldn't choose not to be. But I'm a more settled person. In many ways my life has just begun

J. Lavender

Dear Asperger United

letters to the editor

Dear Sir

Many thanks for your continued support via the *Asperger United* newsletter. It is much appreciated down here in the far west.

I write because of my experience here to ask whether other AU readers have had the same. I read in each AU that 'I am a ... year old, and have just been diagnosed with Asperger syndrome'. How accurate do they feel the diagnosis is?

I have had problems ever since childhood, but it wasn't until I was 50 that I had the chance and time to try to understand my situation. I have had: 1st diagnosis – definitely not Asperger's, 2nd diagnosis of depersonalisation / derealisation, and a 3rd definite diagnosis of Asperger's to which my GP and psychiatrist have said on separate occasions that whatever specialist you see you will get a diagnosis of whatever they specialise in. This statement dumbfounded me, as I feel that my diagnosis has been unsafe.

I have been tried on many medications depending on each diagnosis, none of which has helped.

I wonder if any other readers have had the same experience, what medication have they been given, and what help in general have they received.

Many thanks for your excellent publication.

L Haag, Cornwall

ROOM TO LET

I'm Alan, I live in a quiet village about half way between Bristol and Weston Super Mare and currently have a room to rent in my house. In fact to be accurate it's two rooms, a bedroom and a study. The kitchen, living room etc. would be shared with myself. Facilities include dishwasher, washing machine, DVD/Video, Sky TV etc. An internet connection to the study can be arranged. There are good train and bus services to Bristol and Weston. Rent is negotiable and if you're on benefit that's not a problem.

I have Asperger syndrome and don't have many visitors so you can be assured the house is usually a quiet, restful place. Tel 01934 835903 or write to me c/o *Asperger United*.

Dear John Joyce

Greetings. I am writing after receiving the latest edition of *Asperger United* (edition 35, July 2003). I was reading the 'letters to the editor' section (page 6), and the letter from Marianne specifically, and wanted to supply some of the information Marianne was enquiring about. Firstly, 'cheers' Marianne for the compliments in relation to my artwork. Unfortunately, I don't have a website but I am a member of ASPIRE (the York social skills group) and they are intending to create a website. I have been asked if they could use some of my artwork on this, which I have agreed to. Hopefully it will include things like music, photos, poems and writing too.

Anyway, when this website is up and running it should be possible to access some of my pictures and also things from other contributors. I hope this info is helpful to you.

Peter Myers

Dear Readers

I was born on the 5th July 1983. My parents found out that I had Asperger syndrome when I was eight, although I found out a little later when I was nine or ten. A few years back, people tried to get me to:

- 1) Explain myself
- 2) Be less shy

I have done what they wanted me to do and I get nothing back in return, plus I get ignored and I'm not given much sympathy. I feel betrayed and conned. I always think before I speak and before I do things and I am rarely successful. It is as if it does not matter what I say or do, I will not succeed. Does anyone feel the same way as I do?

I felt sorry for Lucie ('It's good to talk' -AU July 2002) when she wrote about her school life because although I had odd habits too, my time at primary school in Cambridge was enjoyable because I felt that everyone in school were my friends and I was rarely picked on. My mum reckons that it was probably because I was a nice boy and the other children ignored my strange ways.

I know a friend who had Asperger syndrome and he had a similar life to Lucie, in the fact he had a sad childhood, but now he is an adult he enjoys his life much more.

Alex Radford, aged 19



Pen Pals

- •Please remember to let us know the full name (including surname) of the person who your letter is for.
- •To contact a pen pal, please send your letter to Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.
- •We will pass your letter on to the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.
- •Please note that all penpal letters sent via Asperger United are opened before being passed on
- •Young people under the age of sixteen must have parental permission before placing a pen pal advertisement in Asperger United.

My name is Robert. I have
Asperger syndrome and live in the
Newcastle area. I enjoy walking in
the countryside, cooking, shopping
in town, and eating hamburgers.
My hobbies include 1960s' music,
particularly Cliff Richard;
watching television especially Top
of the Pops 2, soaps and old comedies. I would like a female penpal
to write to and possibly meet.

Hi, I'm Amy, I'm 18 and I've got AS. I live in the West Midlands and my interests, among others, are song writing, the internet, Harry Potter and the Spice Girls.

I'm looking for a penpal of any age, gender, sexuality, location or race and, although it would be nice, it is not essential that we share the same interests. The only requirement I have really is that you can speak English (although of course this doesn't have to be your first language.) I hope to hear from you soon.

My name is Rick, I'm 23 years old, I live in the Slough area and I have Asperger syndrome. My main interests are films and writing film reviews and I would like a friend, preferably female, to accompany me to the cinema. I work part time in a video shop and also attend college. My other hobbies are running, going to the gym and swimming.

My name is Carla. I am 19 years old and I am looking for a pen pal in or near the Cardiff area. I was diagnosed with autism when I was three years old. My hobbies include walking, clubbing, karaoke, going to the cinema, meeting new people and learning something new.

Hi! I'm Robert. I'm 30 years old with AS. I'd like a female penpal (28 to 30 years old) on Guernsey or in South Devon, with or without AS. My hobbies/chief interests are collecting old Ladybird books, learning modern languages, travelling around the British Isles, local history, bird watching, football, Italian cars and 1950's fashion.

My name is Cameron. I'm 24 and live in Edmonton, Canada. I was diagnosed with AS in my early 20's. I'm looking for a friend who would like to share some of their thoughts and life with. I would prefer to email or talk on msn messenger. Some activities I like doing are working out at the gym, spending time with the dog, reading self improvement books, listening to all kinds of music, surfing the web and dancing. I am currently working on achieving an apprenticeship. We don't have to have the exact same things in common, but celebrate our differences. I am looking for friendship first and also with someone to share with the dealings and trials that come with Asperger's.



Asperger's - the hidden hindrance

Growing up as an eldest child always carries some form of responsibility, no matter the country, race, gender or time of year born into. The younger siblings will inevitably look up to you as a role model for some kind of guidance as to how to act in life, and the parents look upon the first born with some kind of unique parental pride. People like me, Asperger sufferers, find this hard to comprehend and deal with. How do we act in regard to setting the example? What things are we supposed to say? Do we meet the 'normal' criteria of a first-born?

Questions, questions, questions, something I primarily had an endless supply of when first diagnosed with this form of autism back in the summer of 1999. What is it? How did I get it? How do I know I have it? What do I know? This piece will hopefully educate you (and, to some extent, myself) and let you step inside the mind of an AS sufferer.

When I was younger I saw myself as different from the rest. In primary school I always seemed to finish my classwork faster than everybody else and ended up having to help the others catch up. I also had an intense fascination with drawing and writing, and in particular numbers and dates. Many weekday afternoons were whiled away designing calendars, many a rainy holiday filled with a statistical chart or a numerical table of some sort. This appeared somewhat strange on discussing the holiday activities with fellow peers. Their tales of hours spent idling away in front of the latest Turtles or Super Mario game seemed, although interesting and worth a try, a trifle wasted to myself.

I always seemed to be the only one who actually wanted to carry on with the work when we didn't have to, but only if it involved numbers or data of some sort. Except that I never saw it as work, I saw it as fun.

Something about numbers and dates generated (and still does to some extent) immense satisfaction and interest inside of me, a later to be known (to me) common trait amongst AS sufferers.

This changed somewhat when I realised I was alone in this. Never having been one particularly to enjoy being the centre of attention (at least outside the family), I began to take things a bit easy, so instead of rushing to finish my work in every lesson and then help others with the same exercises, I would just not do my work, or at least not do it to the best of my ability. This carried through to secondary school where I was never the best or the worst in anything, just muddling through in mid-table obscurity. I was quite content to do the bare minimum of work, nothing more, nothing less and always remain in the same bracket, never quite achieving what I had at first appeared capable of, to my parents now all too obvious chagrin.

It was about this time, the early 90s, that I began to develop an obsession with the game of football. Trying to keep us quiet during the summer holidays on a visit to a café, my mother bought me some football magazines. I was instantly hooked on this game I had already observed from a childlike distance and taken a passing interest during the previous World Cup in Italy and the annual Cup Final TV programme that remained a 'must watch' during my father's dormant 'Saints' supporting years. I can remember sitting on the stairs feeling disappointed when my dad informed me that the 'festival of football' (The 1990 World Cup) wouldn't be back for another FOUR years.

My condition spiralled from there. Every magazine had to be bought, every television highlights programme had to be taped for this ten-year old to watch the next day after school or church. I also took a bit of pleasure in being the one to reawaken my father's fawning interest in the game and also enlightening my brother to the (to me) wonderful game. Every Spurs match became an event to me, the days leading up to it spent predicting what was going to happen, the days after dissecting the performances of the team and players. This is what most fans do anyway, but to me it always seemed to be that little bit more serious, that little bit more life-controlling.

Even now, when I go on holiday with the family, I always make sure I have some way to keep up with the latest Tottenham scores (for it is on them that I have bestowed my love upon). Past family outings were majorly influenced by the need to find a radio to listen to the match or check on the final scores.

This football affinity also led to my discovery of newspapers, the original media. Newspapers had always been around in my life, my dad always buying the Evening Standard, with the Independent on Sunday providing 'something different' at the weekends. They always seemed fascinating to me, a (relatively) cheap 'factual booklet'. Something full of information, statistics to digest and news to take in and mull over. As I got older I became aware of the tabloids and their extensive football coverage, with a lot more pictures than your average broadsheet, illustrating the beautiful game to this fan who had to rely on terrestrial outputs for his weekly fixes, only dreaming that the hyperbole surrounding Sky Sports and their extensive Premiership coverage would ever reach my television. The papers offered me a way into football. I can remember begging the nice old lady four houses down from us for her copy of The Mirror every day after she had finished (a friendly nod is still

exchanged today). I would immediately turn to the football pages at the back of the paper and devour whatever delights appeared that day.

As I began secondary school the daily trip to the newsagent opposite my bus stop became a pilgrimage as I picked up my own copy of The Mirror every morning.

My best friend's unwanted coupons for free copies of The Times were accepted with glee and introduced me to the daily road map that is the broadsheet newspaper. Their extensive reportage and brilliant graphics (something *The Times* excels at) turned me into a fan and I began to get that newspaper every day as well.

I feel that all the papers I buy and the amount of time I spend reading them compensates in a roundabout way for my not reading books. I have never really had the staying power for books; I think I have only voluntarily read about four books in my life. By the time I reached 16 I was buying three papers every day and had started to keep scrapbooks of Spurs matches. Any newspapers I bought I would and still do keep until I read them, leading to immense piles of unread newspapers building up around my room. If there was a story which contained anything I was remotely interested in I would tell myself I had to read it and I think the rigidity of thought that assumes most Aspergics came in here. Every paper's cartoons had to be read, every Tottenham story had to be cut out, every TV guide had to be read and so on.

It became boring and repetitive after a while, but there was something telling me I had to do it. I brought the paper and it would be a waste if I didn't read everything that even remotely interested me. Things have improved a bit now, although I still buy a lot of newspapers, I think, mainly, because I

always have and perhaps always will.

Even when I went on holiday to America last year, I couldn't contemplate missing my favourite writers and the regular football coverage I had become accustomed to, so I arranged for a friend to keep all the newspapers I missed for me until I returned. It amounted up to something like fifty papers over the three weeks we were away. I felt a little bit bad about putting my friend out, but my love of papers still led me to ask him to undertake such a hefty operation.

Asperger syndrome takes its name from an Austrian scientist, Hans Asperger, who identified and defined the condition in 1944. It wasn't until 1981, however, that the syndrome was given a name, Lorna Wing naming it after the man who identified it. It is estimated about one person in every three hundred suffers from some form of AS, with the majority (90%) being male, with a ten to one ratio.

The symptoms of delayed development, no appreciation of conversation and pedantic speech can be attributed to most men anyway, which probably shows why most sufferers are men, their life patterns so similar to begin with. Indeed, the symptoms are so similar that my 'claims' to be Aspergic have been ridiculed by a couple of people I have told. They just see what I am supposed to be like and say, 'There's nothing wrong with you, you're just a typical bloke, we're all a bit like that'. I guess there is indeed a little bit of Aspergers in everyone.

When approached with new situations and new people to talk to, particularly on one's own, I tend to get anxious and perspire a lot, even on a freezing cold day. The situation is obviously worse on a warm summers day, leading to my trying to cover the large underarm patches

of sweat by wearing a large winter coat, to the annual amusement of others. 'Aren't you hot, James, in that ridiculously large coat?' can be heard year after year, to which I have no option but to reply with a curt 'No'.

Asperger syndrome has also led to me having low self-esteem. Time and again in class or at work, church or at home, embarrassment and self-consciousness have kept me from spewing the contents or opinions of my mind.

Everyone has an opinion, they say. Well, everyone except AS people. I also have persistent difficulty in initiating and sustaining relationships with other people. When they are speaking to me I frequently find myself in awe at the fact that they can speak so confidently, so fluently, so full of purpose, whereas when it comes to my turn to speak I tend to hate the sound of my voice so much that I say the bare minimum (hmm, there's a theme here) and hope that'll suffice.

Eye contact has also been a problem, I find it remarkably hard to locate and maintain contact with someone's eye, although this is gradually improving. I have always found it hard to determine exactly what the problem is with eye contact; perhaps it is something to do with my emotions and the difficulty in showing them. I sometimes catch myself thinking about the person I am supposed to be looking at and thinking that there is a whole life behind those eyes, a whole load of experiences that I have no recollection of and who am I to speak to them on a friendly basis (or not, as the case at work may be). This does sound outlandishly silly as I type it now, but it is honestly what happens.

A further trait of Aspergics is their habitual need for a rigid structure to their day. I personally like to

know what I am doing every day before I get up. As previously stated, I get anxious in new situations so always like to do similar things so I know what to expect. If my mates say 'Let's go out, which pub do you want to go to?' I always say the same one we went to last time, purely because I know the layout, the decor and know what to expect. This can be awkward because of course we can't always go to the same place and it won't be the same forever. But gradually, as I get older and more settled in my adult life, I feel this is improving, too.

"They often have obsessive routines and may be preoccupied with a particular subject of interest."

Another common trait in Asperger sufferers is that they often excel in subjects, hobbies and work that require a good deal of remembering and a lot of intense concentration.

They can excel with facts and figures, to an extent that bewilders and confuses others. This can come in useful, for me in the workplace, where working out metric conversions and (what some would) perceive difficult mathematical equations on the spot is always going to be a bonus.

The memory 'feat' can also be seen as remarkable to others, Aspergics having uncanny abilities to recall even the smallest details of events with extraordinary clarity. This writer's afore-mentioned bafflingly intense love of football leads me to be able to relate back to large portions and episodes of my life by merely remembering a match or football news story that took place at that particular time.

To give an example, by going back to the Euro 96 match-up between England and Holland on June 18, I can recall what happened that night, my watching that first Shearer penalty hit the back of the Dutch net

just before my dad and brother rushed in, having been held up in a car journey (from where, who knows? I didn't say it was picture perfect!). This helps me a lot as I am able to remember things I was told, like places to meet up or things to tell people, family events such as birthdays and anniversaries and also things that I need in life, like a certain piece of information for a test, whether or not someone has paid me back the money I lent them, or when exactly the order for the bed was placed and exactly how long we have been waiting!

Additional 'qualities' displayed by Aspergics are a great ability with the mother tongue, an acute sense of taste, smell, sight or noise and also a fear of public or even private speaking.

I am consistently asked to explain what a certain word means, usually when I have gone over the top in a piece of writing and used some fancy word like 'beleaguered' or 'demonstrative'.

The acute senses frequently leave me frustrated. A normal and perfectly innocent Sunday lunch or evening meal can be (and usually is) hell on earth for me, my hearing magnifying the sounds of people grinding and crunching, slurping and burping. This can sometimes lead to me making inappropriate comments merely due to the uncomfortable-ness of the situation I find myself in.

I also seem to pick up weird and acute tastes in my mouth when eating certain foods, which puts me off them for life. To my teeth's detriment this mainly occurs with vegetables, whereas the numerous fizzy drinks and confectionary items I care to pour down my throat are accepted without any hesitancy!

The fear of speaking is highlighted in every day of my waking life. Going down to the local newsagent or passing the workplace and having a two second chat with my boss can require a planned 'speech' or a pre-determined subject to talk about.

Waiting at the bus stop, in a football ticket queue or in the line for lunch is also usually conducted in silence.

I guess the fear is that I have nothing interesting to say and that anything I attempt to say will be verbally gunned down and ridiculed, as has happened, to some extent, in the past. Anything I do say will invariably come out quickly and with no meaning.

Having just headed into work, waiting for the first customer to come in and ask for a bit of four by two or a sheet of ply or something along similar lines, listening to all the other guys talking about the latest problem they have with their car or whatever humorous event has brightened their week, I am left there in the corner, not having much to contribute except the usual curt 'Yes' or 'No', or maybe a quick 'Shut up'.

Writing it all out like this makes it seem ten times worse and of course, having been there for four years they have grown accustomed to various habits and nuances. But some AS sufferers aren't exactly so fortunate or 'lucky' to have the loving family and work environment I have. They find themselves on their own and have no support arrangements of network of family and friends to fall back on.

I guess I am pretty fortunate to find myself in the situation I do.

James Mariner Journalism student London

Thank you James - you speak eloquently through these pages. I hope this work spurs you on to greater things - John Joyce

Work experience at the NAS

My first impressions of The National Autistic Society upon arrival were mainly that a large number of the people employed were women. I always wonder whether it's illegal for men to do certain charity work, because this is also the case at another charity I regularly visit. However, it was explained to me by someone that women do charity work more than men because it's usually a low paying job, and women don't really care how much they get paid.

In any case, the people who I worked with were all very nice, even though some of the work was rather boring. I remember spending a lot of time proof-reading a book called 'Inclusion in the primary classroom', which was about to be published by The National Autistic Society. The problem was, that it had already been proof-read, so a lot of the more noticeable errors, such as the spontaneous references to 'Autism Spectrum Disorders', had already been corrected. However, ideals of grammar being one of my strongest topics, I was easily able to ferret out many confusions of 'that' and 'which', as well as some other things, most of which were silly little things that no one would notice in a million years, so a Microsoft Word grammar check would never pick them up (when it blatantly should, rather than doing pointless things like picking an everlasting fight with the passive voice!)

Other tasks that I was made to do in publications included the fabled

slave job of photocopying. But in actual fact, the photocopier that they have at the NAS is a very clever machine. I'd never heard of one which has a built in laminator and stapler, as well as the special double sided print things it can do! The only problem with it is that it's a complete wussy. It crashed twice when I was photocopying massive 72-page booklets on Asperger syndrome, (which reached approximately 40 degrees Celsius in temperature by the time they came out of the other side), just because I gave it an accidental tap with my foot, and I was reduced to a despairing heap on the floor whilst I tried in vain to fix the problem. Finally I managed it. and five minutes later it happened again. However, I was quicker fixing the problem this time.

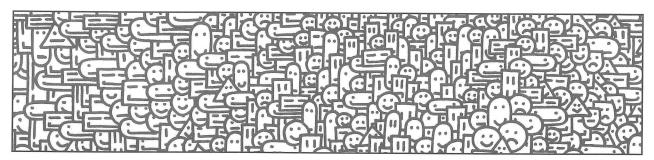
Overall, I didn't think photocopying was a slave job at all. The slave jobs I had to do whilst I was here were mostly in the Information Department. I was greeted on Wednesday morning by several huge bookcases, full of A4 filing boxes. which contained books on autism. I was made to stick labels on these books indicating which category they fall into. It took ages. I was almost dead by the time I'd finished, well, my hand was, at any rate. And what's more, having said that, I never actually finished! I had barely got through a fifth of the books on those shelves when I'd given up!

One of the people in publications also requested that I type up some articles for Asperger United. One of these took me 3 and a half hours but was a rather interesting account, called "The Guards". It talks in length about many things related to the military forces, and the old toy soldiers! (To be published in a forthcoming edition of AU).

Overall, however, my work experience at the NAS has taught me a few very valuable lessons. One is that it would be unwise for me to work in Information when I grow up, seeing as the work I did there was mostly to my great distaste. Although, it has occurred to me that although people with autistic spectrum disorders are likely to be shunted down in society, they are obviously still able to get jobs, because during my time here I met several people who had autism or Asperger syndrome.

Seeing as I'm now in the very familiar world of people who have nothing else to say, I'm going to stop typing this thing now. If you've actually read this far without getting bored and turning the page, well done. In any case, for all you people who are just about to undergo work experience, if you foresee yourself working in a standard, mainstream office job when you grow up, I would strongly recommend that you consider taking your work experience somewhere like the NAS as I did, especially if you have an autistic spectrum disorder.

Sam Robinson Aged 16 Publications Dept.



Peter Myers

Asperger Syndrome in Newham

My name is Philippa Hembry and I am currently working in Newham, East London. My role is to identify the needs of people over the age of 16 years who have Asperger syndrome or high functioning autism. Once people's needs have been identified, services that meet these can be developed in Newham.

This is a call for information!

Do live in Newham and have Asperger syndrome or High Functioning Autism and would like to be involved in this project?

Do you know of any services for adults with Asperger syndrome or High Functioning Autism in Newham?

Do you know of any services run elsewhere for adults with Asperger syndrome or High Functioning Autism that

work well and are examples of good practice?

If you live in Newham and would like to contribute to the project then please contact me at:

Shrewsbury Annexe Shrewsbury road Forrest Gate London E7 8QR

philippa.hembry@newhampct.nhs.uk

Or call 020 8586 5021.

All contributions welcome!

Philippa Hembry Newham

New video news

Outside in: living with Asperger's syndrome - Paul R. Smith

We are delighted to recommend this video to readers of *Asperger United*.

Outside in has been produced by the people who know most about Asperger syndrome: people who have Asperger syndrome.

This new, high quality video about Asperger syndrome is the work of a group of people with Asperger syndrome in the Coventry area.

Outside in focuses on three men with Asperger syndrome who talk about themselves, their interests and anxieties. Larry Arnold, one of the men on the video, is also a member of the Council of The National Autistic Society.

It is an excellent resource for anyone who wants to know more about Asperger syndrome. This video is published by Paul R. Smith and costs £15.99.

Special offer to readers of Asperger United!

Normally we charge an additional £3.95 postage and packing on publications orders but readers of *Asperger United* can get their copies without this additional charge until 15th November 2003.

Just send your order, together with a cheque or postal order for £15.99, made payable to the NAS, to *Asperger United* – see page 2 for full address details.

Please also send us news about any other videos or books that you think readers of *Asperger United* should know about.

COMPETITION WINNER

Congratulations to Richard Wiles, the winner of the competition we set in the last issue. Richard will receive a copy of Gunilla Gerland's book, *A real person*.



