

Produced by and for people who have autism-spectrum conditions

Asperger *United*

Edition 67 July 2011



Asperger United

Asperger United is a magazine run by and for adults with autism-spectrum conditions (although some parents subscribe on behalf of their under-sixteens). The magazine aims to put people with the condition in touch with each other and to share information so that they can lead more independent lives.

Please note that *AU* receives over 200 letters each quarter so it is not possible to respond to every one, nor for every contribution to be printed. *AU* protects the identity of contributors by not printing full names unless the writer asks for his or her full name to be used.

Asperger United is free. To subscribe you, we need your postal address. We ask for a contribution of £6 per year from overseas readers and £10 from professionals and institutions to cover postage costs. Please make cheques payable to the NAS. Organisations requiring multiple copies: no extra fee, please get in touch.

Editor the Goth

Telephone and production support

The National Autistic Society's Publications Department

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, John Joyce and the current editor, the Goth (who does not wear black).

Pamela Yates provided support and advice to the editors until the publication was handed over to the National Autistic Society 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.

Please send all correspondence and subscription requests to:

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Fax: 020 7833 9666

Email: asp.uta@nas.org.uk

All we need is your name and address and we will add you to the mailing list — free of charge.

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 issue should reach *AU* by **15 August '11**

Welcome to the July edition of *Asperger United*. The NAS has made a number of small organisational changes this quarter. Thanks to some generous sponsorship, the NAS Helplines are now free (again) from landlines and most mobiles (the smaller mobile services haven't yet agreed to join the scheme). The main Autism Helpline number is now **0808 800 4104**, though the old one still works. Also, the number to use to contact *AU* has reverted to **020 7903 3595**.

Emma, the photographer from last edition has been in touch with her web address:

www.egophotography.tk

so everyone who can get on line and who wants to see more of her work (and many wrote in asking for details), enjoy! Apologies to those without Internet access, but in these circumstances, it's not clear what else I can do.

This edition also has contributions from two people called Dave, two people called John and two people called Jane. There's even a Sean and a Shaun. I think that's a record. If you write in about one of them, please make it clear which one you mean.

Lastly, one of the suggested themes for this edition was addiction, and I received many letters urging me to make addiction the theme, including three from parents who told the stories of their alcoholic sons. Apart from these three, two people contributed (one of which appears in these pages). This is a magazine written *by* its autistic subscribers, so the only way to see pieces about the subjects you want is to write a piece yourself. If it's a popular subject and others do the same, then there will be what you want in the magazine. But it has to start with you — happy writing!

the Editor

not the addiction edition (with a lot about social — especially technological — exclusion) — next issue notice on page 15

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feature

Dear *Asperger United*,

firstly, I would like to say how much I like the new look of *Asperger United* and its breakthrough into the multicoloured universe. This can only add to its potential and appeal. Great stuff.

I liked the cover artwork by Emma for *Asperger United* edition 66. It is quite a powerful image. I tend to draw, paint, or make things.

It reminds me of drawings, paintings I used to do. I know the feeling, the experience of that. But I think I have moved on from this. Now my artwork, life, is calmer. The experience of autism need not be negative and when one has found inner acceptance, peace, and the demons no longer torture one, then one's artistic potential can grow and move onto expressing other, more positive experiences or subject matter.

Art for me is therapeutic, so in expressing negative aspects, it can help me to see these more clearly, and in some way come to terms with them. And expressing pent-up emotion in art is a great release of energy, may help one to be very productive, and can lead to some great art.

Moving on, I was interested in the article *Computers: friends or foes?* It reminded me of something I wrote last year:

I was born in the Sahara during a sandstorm, on the first of June, 1959.

When I went to school I had no experience of computers: they were not there, they did not exist in my education. At college I did design, so again they were not there. Throughout my working career, in factories, my work was more hands-on, so did not require I use a computer. And in my home environment I have never felt any need to own or use a computer.

I am largely computer illiterate, so am, in effect, deaf, dumb and blind to the world of cyberspace. It is not how I access information, it is not how I communicate, or how others may communicate with me.

It is not that I dislike computers. I actually like computers and find them fascinating. I like documentary programmes about computers and I love science fiction, so how could I not but like computers? No the big difference is between theory and practice, and this is what I lack.

I have no difficulty with others making a life choice to become reliant on computers, to access information, communicate, or even to socially interact this way. This is their preference and I respect that. However this is not a desire I share and I wonder what all this has to do with me?

I know that I am not alone in this difficulty. Apparently some 30% of the population of the UK neither own nor use computers (mostly the elder, more mature adults).

Despite the fact that this disconnected minority (even if it does represent many, many people, many millions of sentient beings) exists, it seems to go unnoticed by the dictatorship of the majority who seem intent on changing the means of communication, or controlling access to information, in an addiction to modern technology. Some of us do not function this way. Some of us are not "techno-clones".

I think the notion that autistics tend to favour communication by computer is something of a misunderstanding, not universal, and thus not wholly true. The misleading assumption that this is so is not helpful, and may present real difficulties for some 30% of the population, autistic or not, who, like in the film *Apocalypse Now*, may find a kindred spirit in the dialogue, "Charlie don't surf."

I think none of us would wish to be excluded, sidelined, or ignored. And I hope that others would not intentionally aspire to do this.

However, some supply only a website address with which to communicate, which is as much use as a "chocolate fire guard" to someone who neither owns nor uses a computer.

I might argue that it is a violation of my human rights, discrimination, or, at the very least, treating me as a second-class citizens. Supplying a website address is fine, but unless this is accompanied by what is for me more relevant, postal address, and telephone number and I am to all intents and purposes barred from access.

I find it somewhat annoying that simply because the modern world has changed how it communicates, it seemingly demands that all others do likewise. Who decided that such things be compulsory? Where is my "opt-out clause"? Where is my choice, my freedom to choose? I find such enforced change incredibly arrogant.

I have a system in place that works just fine, and it has taken a lifetime to learn this, half a century and more, and at my time of life I have no wish to change this. It would be like learning a foreign language.

Are then computers friends or foes? Well for myself, if something is forced on me, then this is not a friendly act. If I am no longer able to communicate with others and access information, then this is social exclusion, isolation.

If one decides to join this world then it may be necessary to buy a computer and all the technological attachments that go along with this. These things are not cheap, particularly if one's like myself, on a low income. And this expense seems never to end: paying for broadband, getting a landline, paper, ink cartridges, and so on.

And one may require the space for all of this stuff, which again I lack. An interest of my own is doing artwork, and this takes up rather a lot of space in my humble abode.

A great advantage of the modern computer is that it opens up an entirely new world. All kinds of information and all kinds of people become accessible. There are music sites, art sites, sites of all kinds of special interests. One may peruse in detachment, or indulge in Internet chatrooms and social chitchat, interaction.

One thing I like about communication by writing is its detachment, and that I can communicate at my own pace and without social distraction. This differs from communication by telephone, in one-to-one real-time social interaction, or the anxiety of communication to several others simultaneously. I can see how communication by computer is similar to this.

One can send an e-mail to anyone in the world who is also connected and this is much faster than conventional mail, and far cheaper too. However, some people do not always reply to their e-mails and some may not even read them.

Being online does have its drawbacks too. One may be inundated with spam. There are also computer viruses. I was doing some computer training once at work. I was accessing an autism website and suddenly the computer screen was filled with pornography which seemed in no way related to autism. So I pointed this out to my supervisor and she agreed it was one of those computer viruses, someone's idea of a joke.

Viruses can do many antisocial things, as may hackers, who may steal information held on one's computer. One need only think of the recent Sony debacle, with hackers obtaining 73 million data files on those that use that system. This includes personal information, which may be used by the hackers for identity theft.

So it is very important to have good antiviral software (yet another expense) and to keep passwords, personal information safe (is this site safe? Is the person one is communicating with a safe person?). And as in the case of Sony, even if one does all of these things, a hacker may still obtain this information indirectly. That is a disadvantage of the Internet; one is connected to others, and others are connected to you.

So to sum up, my own conclusion is that people should still be able to function without a computer. They should not be socially isolated simply because they do not do computer.

Peter

a letter

Hi Goth

I feel I must write a response to the article *Sensitivity and clothing*.

53 years young male. I would like anyone locally to contact me. My interests are watersports; I am aiming to go coasteering later this year at Bude and would like someone to go with.

I too suffer a similar problem but in reverse. I cannot stand being uncovered. I had third-degree sunburn as child of 9 in Australia and still burn very easily so have remained covered up ever since. I prefer tight clothing over my entire body. I wear sportswear, tracksuit and football kit over my tracksuit all the time. I also wear female swimwear over everything including bikinis. I also swim fully clothed as I cannot stand the feel of water against my torso, yet I am mad on swimming and watersports. It is here where the harassment and torment come from people "who just assume". I am judged by what I wear as a "queer, poof, paedophile". I have been harassed by the police with warnings and in one case receiving a ticket warning. This eased when I threatened to sue my local police force under two sections of the Human Rights Act, sections 8 and 10. Whilst I admit to most what I wear is odd to many, to me it is normal. Colours also vary according to my mood. The few people who have taken the trouble to get to know me have found underneath I am a fairly "normal, intelligent, resourceful" person. It has caused some problems with my parents and brothers and sister. When I go out or shopping I will wear a tracksuit with shorts on the outside.

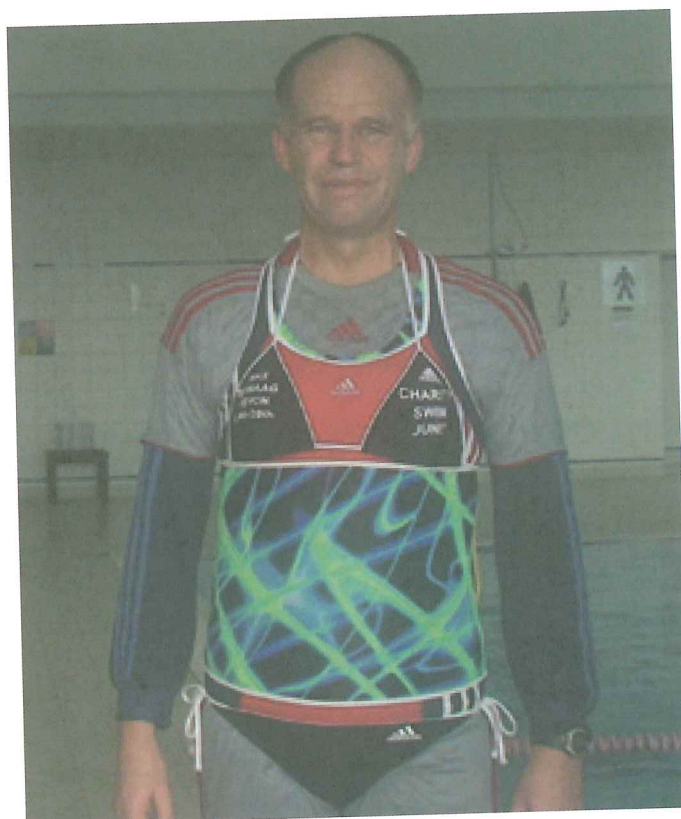
To help raise awareness of the condition I helped organise a charity swim last year for NAS-SOMAAG-Devon at the Esporta Devonshire in Plymouth and the Pyramids in Exeter. I swam fully clothed with seven other swimmers. In total swimming 2,650 lengths of the 25-metre pool. I did 501, see photo. In total raising £1,928. When people do ask why I am wearing what I am, I tell them about the condition I have and how it affects me.

A classic point in question. One paragraph from my soon-to-be-published autobiography *Bikiniboy — living with Asperger's syndrome — the story of a secret lonely double life* with forewords by Tony Attwood and Barbara Wilson. Whilst sunbathing one day (rare for me as I burn easily) I was wearing my pink bikini. A group of three teenagers began to shout abuse. One came over, intent on beating me up. I challenged him saying: who did he think he was? Everyone has the right to wear what one wants. His answer was "I hate queers". I replied: I am not queer but autistic. They then left. Later they came back and, surprisingly, apologised. The threatening one said "We hadn't realised, but just assumed, anyway I can understand now, my younger brother is autistic".

I was diagnosed with AS in 2003. I was not told about the NAS at the time but referred to Mind who said they could not help. I only found out about the NAS in 2006 through my business manager. (I run a business helping charities, groups and clubs with their fundraising).

Regards

Dave



Pen pals

Pen pal number 85

I am a 40-year-old lesbian (don't be fooled by the name) with Asperger's, from the south coast but living in Northamptonshire. I also have schizophrenia and type 2 diabetes. I was diagnosed with AS nearly two years ago. My interests include ornithology, creative writing, astronomy (especially meteors), humanism/atheism, mental health and autistic spectrum issues, languages (especially Spanish, Dutch, Welsh and Russian) and nephology.

I'm also interested in hearing from Asperger people who've started their own businesses (successful or not).

Shaun

Pen pal number 86

Hi, my name is Richard, I am 43 and was diagnosed with Asperger's in 2009.

I live in North Hampshire with an elderly dog and cat. I am separated, but managed to remain married for seven years.

I do not have much in common with the people that live close to me and only really see my father on a regular basis.

I am trying to build a career in Environmental Conservation and also become an advocate for people with an ASD, but I am still trying to find my way. My interests include: conservation work, science and technology, reading, Radio 4, classical music and caring for companion animals.

How to place a pen-pal advert

All you need to do is send your advert along with your name and address (and email address if you want) to *Asperger United*. You can use the Royal Mail or email. The next pen-pal number will be given to your advert when it arrives.

How to reply to pen pals

- Please remember to let us know the name and number of the person whom your letter is for. (All pen pals are numbered by the editor, not the person who sends in the advert.)
- 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 pen-pal letters sent via *Asperger United* are opened before being passed on.
- Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.

****Important notice — please read****

Asperger United is happy to publish pen-pal advertisements but we must stress that we are not a pen-pal or introduction organisation. We do not match people up and we cannot monitor letters (other than the first letter, that is sent via us) so please be cautious when releasing personal details in your letters. The National Autistic Society / *Asperger United* cannot intervene or be held responsible for any ensuing correspondence between letter-writers.

Pen pal number 87 is Dave on page 6, who begins his letter with a pen-pal ad. Also, three pen-pal ads have been held over for the next issue, Ed.

Pen pal number 88

Hello, my name is Adeinne.

I live in Glasgow and am 19 years old with Asperger's syndrome and got diagnosed a few years ago.

My hobbies are surfing the Internet, animals, watching videos on Youtube, arts and crafts, DVDs, going to the theatre, science, travelling, playing nintendo Wii, playing Nintendo DS and WWE (wrestling).

It would be good to hear from other people around my own age and people that have the same intrests as me.

Pen pal number 89

Hello, my name is Matt. I am 28 years old, live in Devon, I have cerebral palsy and Asperger syndrome, I work for my dad designing websites at his computer company.

My hobbies are basketball, football, watching Grands Prix, Lewis Hamilton, travel. I sometimes find it difficult to talk to people. I am looking to be friends with people a similar age.

Pen pal number 90

My name is Tom and I am recently diagnosed with Asperger's syndrome, so I want to correspond with others who are trying to understand their condition or who have any advice or help they can offer for someone who is newly diagnosed.

Pen pal number 91

Hi, my name is Victoria, I was diagnosed with Asperger's syndrome at primary school. Now I am 19 and a massive Doctor Who fan but also enjoy Top Gear, Waterloo Road, Red Dwarf and Holby City. I am looking for someone who shares any of these interests so we can obsess together.

Don't mind what age you are just as long as you share these interests.

Looking forward to a reply.

Pen pal number 92

Hello, my name is Jacob. I live in North Carolina with my parents. I am 27 years old. I like college football, college basketball, going to the movies sometimes. I like where I work in a machine shop because I prefer to work alone. I like going to the mall to go to the fudge shops and sport shops. I like listening to many types of music (except opera!). I like my faith that I have (I'm Catholic). I also like to cook. I would like to hear from anyone about my age.

PS. I also like to shop at the mall, especially for Abercrombie clothes. I was diagnosed with Asperger's syndrome last year.

Pen pal number 93

Hello, my name is Caroline. I am nearly 18 and I live in Kent. I was diagnosed with Asperger's age 14. I am a creative person and enjoy making cards, painting and scrap-booking. I also enjoy listening to music and playing the keyboard.

I would love to hear from pen pals of a similar age to me.

one more pen pal and a letter to the Editor

Pen pal number 94

Hello, my name is Stephen.

I am from Greater Manchester. I am 40 years old and I live with my parents. I have Asperger's and I would like a pen-friend to exchange letters with who understands the situation.

I try to have different interests. I am not working at the moment but I try different courses.

I have just restarted a keyboard course and I did a cooking course, which was very interesting.

I have a sister: she has a little girl called Lily and she enjoys the magic tricks I show her.

I've been on several good holidays to different places in Greece — with the family.

If anyone would like to write to exchange news and views, please get in touch.

Dear Goth,

it was good to see Elkie's letter about the problems she has with computers (*AU* issue 66). We all know Aspies tend to have problems with learning processes and acquiring new skills. Thus within the autism world we have a divided community. The image of the young computer whizz kid with Asperger's has become a stereotype, and even within the autism-aware community there is minimal recognition of the problems technology is causing older Aspies when they are introduced to it in adult life.

Some time ago a post-grad student advertised in *AU* for adult Aspies to participate in a research survey. She had received a poor response to an online questionnaire. I wrote to her and expressed the view that many adult autists were unable to use computers and suggested she offer a paper copy. Within a couple of weeks she had the number she needed for her sample, and confirmed that many who responded had stated they had not responded before as they were unable to use computers.

My learning weakness is following a sequence of instructions. Don't tell me to go left, right and left again, or expect me to remember the simplest recipe, or I'll be lost and hungry! Thirty years ago a driving instructor described me as the "least promising pupil" he'd ever had.

By the next lesson I'd forgotten everything I'd "learned" in the one before. This type of learning/processing difficulty is common

among Aspies, it formed part of the criteria for my diagnosis at age 44, therefore it isn't rocket science to conclude many Aspies, particularly adults, are becoming more isolated because of technology. I do not have a mobile phone, DVD player or any of the other "indispensable" gadgetry of modern life. I've coined the word "dystechnia" to describe what I believe to be a major and unexplored learning problem among Asperger's adults.

My publisher forced me to get a computer as his system could no longer read the disks from my old word processor. All I can do is Google, e-mail and write text. There is nobody to teach me anything else. That Aspie kids often need specialised educational support is not something we miraculously outgrow. Dumping Aspies into conventional college classes or training schemes with tutors who have no autism awareness is hopeless, and only going to lead to damaged self-confidence.

This issue needs to be highlighted urgently. Even within the autism sphere there is an "I can do it so you must be able to" chauvinism surrounding computers. I receive no autism support from any quarter, the best my GP can suggest is join online support groups. Sure, after I've become fluent in Swahili! Nothing has isolated me more than technology, it was a key reason for seeking diagnosis in the first place.

Tashi delek!

Eric

more letters to the Editor

Dear Editor,

I picked up my copy of *Asperger United* today and I read the thoughtful letter of Lisa, the lady with the 13-year-old son who is concerned about her son's work prospects and is requesting help and advice.

The two most vital problems for autistic people are (1) achieving as much independence in everyday living as they can and (2) the ability to earn a living.

The first problem requires practice and training in household management and entails a lot of patience, perseverance and endurance. To be able to look after yourself and function as much as possible as an individual unit is an absolutely terrific achievement for an autistic person. It is the first thing which must be tackled and must start at an early age. The parents are not going to be there forever and you must never let up on this goal. I am thinking here mainly of the person with Asperger's syndrome rather than Kanner's autism, which I know will be much more difficult. However, the solution to this problem is more attainable within the family than is the second problem, namely work.

In the case of work you need outside help and expertise in the job market. Helping autistic people into work is very specialized and requires people who know the special problems faced by the autistic. Social workers and people in Job Centres do not have the knowledge, expertise or time to make in-depth studies in helping the individual autistic in the job market. This is where I think the NAS could undertake a very valuable service. They could set up a specialised employment unit dealing solely with work opportunities for autistic people. They could become experts on which areas of work are most suitable and they could explore the jobs market and give personal advice to autistic people and their parents. Work is the most crucial factor in the autistic's life. Parents are at their wits' end to know what to do. They need thoughtful professional help and the NAS is the only

organization which has the financial resources and knowledge to provide it. Centres could be set up to provide personal counselling. Work is the most important factor in the life of the autistic. The ability to earn a living puts you on a par with the non-autistic population and is the difference between success and failure in life between self-confidence and debilitating depression. It does not have to be the best-paid job in the world but it represents normality, which is something the autistic is forever seeking.

I am 78 years of age and I have been through the whole gamut of terrible work and life experiences. I was diagnosed with Asperger's syndrome in my fifties and in my early formative years no one knew anything about autism.

I would, however, like to end on a cheerful note to tell everyone that life gets better for the autistic the older you get. I am now settled in sheltered accommodation comprising a comfortable bungalow and I can do whatever I want whenever I want. I don't have to try to socialize or comply with the wishes and strictures of other people. I can live my life the way I want it, and the last few years have been the happiest I have ever had.

Yours sincerely,

Thomas

The NAS has been campaigning on most of these issues for many years, but sadly it is not as rich as you believe. The Prospects employment scheme has been running since 1997, has two offices, in London and Glasgow, and they offer help with job-searching and interview skills as well as support once you are in work and training for your employer and other employees. The NAS also runs some social groups of various sorts, though, of course, we could do with many, many more. Unfortunately, all of the NAS's work has been affected by the economic crisis, but it intends to expand all its services when money is again available, Ed.

Dear Asperger United,

I read with interest Siobhan's article in the January 2011 issue about how important autism training is. I couldn't agree more with the views she expressed!

As an Aspie myself I promote autism awareness whenever and wherever I can. I'm heavily involved in promoting disability rights (including autism) as part of my unpaid work with both my landlord and my support provider. All this started in 2005 and in these six years the panels I've been involved with have achieved successes and goals that comparative "normal people" groups might look at with envy and even jealousy, indeed some are surprised that these goals were achieved by people not expected to succeed. Indeed, one of our first achievements was a "dos and don'ts" poster to highlight and combat anti-social behaviour, reminding *everyone* regardless of circumstances of our *rights and responsibilities*.

In my experiences living in supported housing I've seen the best and worst of humanity. In my first book, *Living with autism in the modern world* (not yet published), I had to deal with situations that "normal" people are allowed to scream and run away from. This was not an option for me as it was like being on a ship that is on fire — you can't run away from it as there is nowhere to go except over the side. I've written about experiences like dealing with anti-social

behaviour, falling out with paedophiles who hated me as much as I hated them, producing artwork — all these experiences are true.

I use my autism to advantage, like always dressing smartly (I always wear a shirt except on a hot day — no hoodies with me), behaving politely and *like a gentleman*. If I was on a date with a beautiful woman I'd be dressed smartly and behave decently. I may be autistic but I have the heart of a gentleman — a young lady once said to me "they don't make 'em like you any more!"

I also embrace the principal of "up here for thinking, down there for dancing" — this to me means using my common sense, my brain and body as one. I do use modern technology but I don't let it be my master: by this I mean that modern technology should be an aide to your social life not the dominant factor. I'm on facebook too but I don't let it dictate my social life — oh no!

Some people think that because I'm autistic I'm disabled and deserving of sympathy (utter tripe). Perhaps their perceptions are down to an unhelpful media and we all know how inaccurate the media can be. In this modern age I've seen what could be described as a favourable swing in our favour, if you *want* to work and are *able* to work you should be given the chance to prove yourself.

Dave

Dear Sir,

I feel inspired to write after reading Emma's letter in edition 66 and seeing her impressive photo on the front cover. She writes about the importance of being positive, *but* I must tell you that it is exactly these negative stories of which she writes which I have found so liberating. I was diagnosed with Asperger's at 58, and after so many years of agonizing over why I am always wrong and trying to make sense of the world, I was absolutely amazed to find that others have had the same experiences, and that I am not alone. Even four years after diagnosis, such

stories often hit on an area which I had not realized before was due to Asperger's.

And as for stories of success, while they can be inspiring, they sometimes have the opposite effect, of making one feel "that's beyond me". For instance, I have never succeeded in getting a single letter published — even those which I feel would have saved lives or helped other people to understand God and the world.

Perhaps this will be the first?

John

The broken ankle

by Judy

I managed to break my ankle and had to spend nearly a fortnight in hospital. Breaking my ankle was bad enough but having to put up with being in hospital with all the noise, change of staff and excessive light, especially at night, was a nightmare. Most of the staff did not know what having AS means.

This is what happened.

I was out with my rambling group and it was extremely muddy. The path was also used by horseriders so the mud had been really churned over. I sank into the mud and while trying to release myself managed to fall and while doing so my ankle turned and broke in two places. I knew it was broken straight away by the pain. Eventually a couple of people from the group as well as a couple of passers by managed to move me to a slightly less muddy spot which was at least flat. I had to remain seated in the mud until the ambulance arrived about half hour/an hour later and by that time I was beginning to feel really cold (it was just before the really cold snap set in).

The problem was though if the ambulance drove to where I was it would have got bogged down in the mud. Fortunately there was a forest ranger around with a four-wheel-drive. So the ambulance crew and others managed to lift me onto the tailgate of the four-wheel-drive.

In order to make sure I was safe, one of the ambulancemen put his arm round my shoulder. He did ask me first and I saw the necessity for it. It was in fact very reassuring. Otherwise I may have slid off the tailgate of the four-wheel-drive.

Eventually we made it to the ambulance where at last I could warm up and get treatment. The two-man crew were great and helpful; I told them about my AS and in this case they knew something about

it. In fact when we reached the hospital they emphasised it to the people at reception. When I arrived at the hospital one of the people from the group met me and stayed until I was transferred to the ward. I was then on my own. I was assessed, had to have an X-ray and had to be sedated and the bones put back into place as it was too painful to keep it the way it was.

I was placed right opposite the toilets so, apart from all the noise and distractions around me every time someone needed to pay a visit, the lights from the smallest room shone straight into my eyes.

A couple of days later I was transferred to the orthopaedic ward. It turned out I was in the gynaecological ward originally.

Here my bed was in a slightly better spot although the ward was still noisy. I needed to have an operation. Although I had treatment under sedation when I first arrived this was a temporary measure and I needed to have screws put in place to enable the bones to heal. Trouble was they could not give me a definite day for the operation. This meant that until the doctors had been around I could have nothing to eat or drink. This could sometimes be as late as 3pm. Finally on Thursday I had the op and it appears it went okay.

After that is when the real frustration set in. I could have been discharged a couple of days later but because of my living arrangements a care plan had to be set up. In the meantime, though, I did get a proper plaster in exchange for the half one put on after the op.

The staff there knew nothing about AS and as a large number of the staff did not really have a good command of English it made communication all the harder.

an article (continued), a letter and a poem

The nights were particularly hard and I was beginning to suffer from sensory overload — very unusual for me.

Firstly, although they did turn off the ward lights there was still light all around. Each team had different routines and some would turn them off at ten and others much later. Same thing in the morning. Sometimes they put on the main lights before seven, other times after eight. We were always woken up about six for an obs. check.

Apart from the light there was constant noise. Other patients using their buzzers or calling out. The staff talking loudly and often new admissions in the middle of the night.

One night it really became too much for me. I was texting people in the middle of the night, was extremely tearful and buzzed the staff several times during the night with all that was going on.

The following morning there was a very understanding charge nurse on duty who had time to chat to me. He agreed I could close the curtains round me at night (something I was requesting but staff refused as they wanted to be able to see all patients when walking through the ward) and wrote it into my notes. Also finally prescribed a sleeping pill for a couple of nights and that also helped.

I finally arrived home having been in hospital for 12 days. Although I am now stuck indoors and likely to be so for several weeks at least I feel I have some control over my life.

Being in hospital for any length of time for anyone can be unpleasant but for an Aspie is particularly hard.

After this experience hopefully I will be able to cope with anything including hopping around on one leg and being very restricted in what I can do as I can't carry anything and even drawing the curtains is a challenge. And having only myself for company most of the time.

On Sensitivity and clothing

I don't have clothing sensitivity problems but I found a couple of points in the article intriguing. Now it's pointed out it is indeed quite nonsensical that school boys should wear long trousers to avoid the risk of cold legs but school girls are safe in short skirts. I also liked the suggestion of male Aspies wearing skirts on grounds of fabric intolerance. Many of us do wear skirts for other reasons but that is a new excuse to me.

On Computers: friends or foes?

I am one of the many Aspies who are quite at home with computers, but I do share the flickering screen problem. I had to set a CRT monitor to refresh at 72 or preferably 75 hertz to avoid it. Another adjustment I find very helpful is to change the background colour from white to a sort of parchment. I can't remember where I found the settings, but they are R:G:B 216:204:184.

John

Sack

Got the sack
Got it back
In a brown paper bag
Fell through the holes
Fell through the dole
Landed on a sack of potatoes
No chip on my shoulder though
I chip away my self-belief
I get a roasting
And I'm not boasting
I put on my jacket of cheese
That melts in the sun's heat

Daniel

In response to Barrey, p11 of edition 63, July 2010

by Jane

I know time has passed since you wrote your article, so maybe things have moved on for you and your wife — hopefully in a positive direction. However, I was moved to respond to the issues you raised, and offer a completely different perspective, as it sounds as though you were really struggling when you wrote the article. I also hope it may help some other person out there.

Your final paragraph questions whether AS can be cured. My view is that there is NO CURE for Asperger's because it is NOT A DISEASE! It is a way of being, how your brain is wired up (like being left-handed maybe). I have AS but I consider myself very normal and a very nice person.

Any mental health issues or relationship difficulties are more the result of your life experiences (especially other people's reactions). Or you could be unlucky enough to have another endogenous condition on top of your ASD. As I understand, endogenous means it's to do with your brain chemistry, etc., so you are prone to the condition (eg. bipolar — which I don't pretend to have any knowledge of, it's just an example) regardless of other life factors.

Regarding other people's reactions, other people can set up expectations of how they expect you to behave in situations. For instance, I am very intelligent. One day I was with my sister and some of her friends. I heard one boy say (to my sister, but clearly within my hearing), "I don't understand how your sister Jane is so intelligent but she's so stupid." He was absolutely right.

The problem was that he put me on the outside like I'm an animal in a zoo with all the neurotypical people observing. He was very young and there would have been no way for him to have understood, because twenty-five

years ago there was so little understanding of the more subtle forms of ASD and no language. For instance, I find the term "neurotypical" very helpful, to describe a condition where the patient is naturally equipped to negotiate the complex social world without thinking too much, and has difficulty understanding things from an Aspie or dyspraxic point of view.

Who is normal?

In fact, Barrey, how do you know your wife is 100% neurotypical?

Before I was diagnosed myself, I could often see ASD traits in others.

I actually worked hard to get a diagnosis. I was getting blamed for so many situations where I failed to perform to expectations and had to be told really obvious things about how to talk to colleagues and customers. I felt stupid when they were pointed out and usually burst into tears. When I finally got told I had Asperger's, I felt proud of what I had achieved, despite my difficulties. Before I had felt ashamed of how I had failed despite my intelligence and potential.

The bleak view that we Aspies can't have relationships is a load of rubbish. Again, depends upon your life experience, or also if you have other illnesses or long-term conditions.

I was happily married for just under five years. My husband chose me and loved me for being me, with my assets and liabilities all included. I'm not sure if he really understood about Asperger's. Maybe that it made me a bit "different". But as we were both different nationalities, cultures and religious backgrounds, we already accepted many differences. He nicknamed me "Asparagus Tips". With his South Indian accent, that was how he read "Asperger's".

an article (continued), a letter and a notice

Marriage is a marathon not a sprint. When you get married, that is where the hard work begins, not ends. All couples have to adapt to one another and develop a way of living together. Marriages where both partners are neurotypical are at just as much risk of failing as any other combination of people.

I don't know what it is like to have your partner push for your diagnosis. Have you asked her why she did it? Do you feel she was trying to change you (or even "cure" you) because she didn't think you were good enough? Or maybe she genuinely wants to help you because she loves you. If I were in that position, using my upside-down Aspie humour, I would use it to my advantage and turn the argument round to say whenever she criticised me — "Well that's because I'm Aspie so you have to learn to accept it". And always get my own way!

Dear Editor with autism,

like many of us I have difficulties with life and there's not much help for people on the autism spectrum. I believe most of us will find it difficult to find jobs because people don't understand people like us. I believe that there should be autism-spectrum day centres, as a lot of us can do jobs, but in places where we would feel safe and people would understand us. I also believe that there should be autism awareness in the learning disability team and the mental health team, as they don't seem to understand people on the autism spectrum and keep putting us from pillar to post and can have devastating effects on us. There needs to be an autism-spectrum team. There also needs to be support for people whose IQ is above 70. The learning disability team don't want to know that even if you're bad with autism, you can have good days and bad days. We do need help. The learning disability team and the mental health team say they can't help people with autism, so where does it leave us? Also I believe that there should be support for people on the spectrum that are gay and straight, women, men, as sometimes we can be in danger of being taken advantage of and

I say this tongue-in-cheek. Of course, seriously, marriage is about considering the other person's needs. And being human is about striving to be the best version of ourselves we can be, so there is always room for personal improvement in all characters. But that also applies to your wife.

I would advise you both to embrace your Asperger's. It is just the way you are, and your wife had some reason to love you and marry you in the first place. So for the relationship to work, she will have to embrace that part of you and not be too critical, unless your behaviour could have bad consequences for you. Eg., if you slurp your soup loudly at your boss's dinner party, and she quietly tells you to stop slurping, then this is for your benefit to keep your professional relationship at its best (unless the boss also slurps their soup!)

it would be nice if there was a club for people who are gay. There should be some sort of club, as we are vulnerable of being taken advantage of sexually, where all we want sometimes is friendship, and the club could discuss staying safe sexually as there is danger of sexually transmitted infections. The same for straight women and men,

kind regards,

Richard

If sufficient material is sent in, the theme for October will be **mental health**, with particular emphasis on the positives of being on the autism spectrum, if possible. Writing on any subject is still welcome, as are ideas for new themes, fillers (for putting in small spaces like this) and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

Aspergirls

by Rudy Simone

ISBN: 978 1 84905 826 1 £12.99 / \$18.95

Jessica Kingsley Publishers

review by Jane

Rudy begins by saying that she only had her diagnosis of Asperger's syndrome when her daughter was diagnosed with it fifteen years ago. She talks about how this syndrome has been treated since then. Misdiagnosis is also talked about, leading to being labelled with anxiety, obsessive-compulsive disorder, schizophrenia and phobias.

According to Rudy, we are in two subcultures, one within the other, because of being very like men in many ways.

Rudy interviews a group of American women who are diagnosed with Asperger's syndrome, using their own experiences and taking quotes. Some of the language terms and experiences won't apply to people who live outside America and you might need to re-translate what they say as you will find some hard to understand or to relate to your own experiences.

Every chapter deals with the everyday things that occur in life, explaining how you could feel when you're in love, when you fancy someone, to what to do and what you should not do when going on a date. Sexual relationships and sexual activity are clearly explained, as are how they are affected by sensory issues and whether sex is painful and annoying. Many of the girls either loved sex or absolutely hated it. I related to wanting to have platonic friendships rather than being a lover of someone in a romantic relationship and found a lot of girls remain celibate, and I found that my lack of maternal

feelings towards rearing my own children were very normal. Experiences of being treated as if the Aspergirl was slow-witted or stupid or mentally challenged are recounted here.

Rudy talks about puberty and mutism together in one chapter and then talks about rituals, routines, logical and literal thinking, and how our behaviour, especially when we lose our temper, is sometimes interpreted as attention-seeking behaviour or faking our emotions.

Puberty is described very graphically. Mutism is often described as being a selective silentness in defence when dealing with bullies, how also thoughts, movements and motor coordination skills become almost frozen, jerky or stiff.

Rudy talks about how lots of Aspergirls will go shopping for the same foods each week even if it is bad for them and, when buying something, asking for the exact number, such as an occasion when an Aspergirl made a food-server count out the exact number of olives she needed, leading to anger and resentment from the server and the lady concerned becoming uncomfortable and embarrassed.

Meltdowns come in two forms: the angry meltdowns and the depression meltdowns.

Depression meltdowns list exhaustion, stomach pain, vomiting, feeling sick (nausea), giddiness or dizziness, headaches, maybe migraines or diarrhoea, and causing breakdowns

a book review (continued), a notice and a letter

and embarrassment. It is interesting the way temper meltdowns are described very accurately and are written just as I experience them, including crying, frustration, shouting, yelling, being sarcastic, becoming vicious, feeling faint or dizzy and that temper meltdowns often happen when we are hungry. Social and sensory overload often happening when people appear to us to be stupid or when they are conning us or ripping us off, and sensory causes, such as touch and pain, also confusion, panic or extreme fear, and being frightened, pushing through and ignoring others' boundaries.

Rudy discusses coping with getting older, and quotes some women talking about welcoming the menopause and that when you age you don't seem so attractive to others sexually but this is welcomed as a relief. Loneliness is discussed in old age and health issues and problems such as food, warm clothes, and safe environments are described as being or becoming a crisis, but would not be so worrying for British readers because of our welfare system. Talking about belief, accepting yourself and accepting support from others, and liking and loving yourself, all spelled out in rather embarrassing, somewhat shocking phrases like "giving the girl some balls", metaphorically speaking, and not literally, of course. There is lots of advice and also positive statements about Asperger's syndrome and its advantages.

Generally I think that this is a quite hard-to-read, technical book and there are a lot of chapters. There is a list of points for parents, and Rudy talks about stomach issues, a discussion on whether Asperger's syndrome is a gift or a disability, and advice from one Aspergirl to another mentioning the use of chat rooms, choosing men cautiously and carefully listening to others, not worrying, just being yourself, cultivating talents. Being happy and happy to be yourself and therefore being popular and liked by others, liking solitude and revelling or enjoying it, living a simple life and being tolerant and being proud of being different, studying and working in your interests, preventing Asperger's from blocking your way. Parents are advised to educate

themselves about Asperger's syndrome, not to blame their daughter or themselves, and not to expect their daughter to be like themselves and not be hurt when she wants solitude because it is her way of escaping from a world that is too fast for her. When disciplining an autistic child, to use simple, non-complicated reasoning skills and not to punish her for temper meltdowns or tantrums.

The hardest part of the book to understand was the autistic diet of casein-free and gluten-free and specific carbohydrate diets, which explained how a leaky gut can't process elements in dairy products, wheat and other grains with gluten. Her rather controversial belief claims these elements allow toxins to flow into the blood therefore impeding or interfering with brain function and development. Lack of gut bacteria and body enzymes are mentioned, which convinces Rudy that autism is caused by lack of these things or too many antibiotics or not being breastfed. Rudy talks about antioxidants and claims they are important and relevant to the autistic and also useful.

This book is available from all good bookshops and through Amazon's charitable scheme at

www.autism.org.uk/shop/amazon-store.aspx

and if you use this address instead of the usual Amazon one, the NAS gets a donation from Amazon.

Dear Editor,

I was interested to read the letter from Eric in edition 66, *Asperger United*, since I am also an Aspie-alkie and am trapped in addiction having been unable to receive the support I need within the totally autism-unaware addiction treatment system.

I would be interested to know what aided Eric in his recovery since I am still seeking help and advice with my problems.

Michael

a letter and a poem

Dear AU,

my name is Sean, I am 21 years old and live with my family. About three years ago I was diagnosed with Asperger's syndrome like my brother, although unlike my brother it is slightly more severe on the autistic spectrum. Without stereotyping too much, I do find social situations difficult and I also have self-motivational problems.

Given the current climate, it would be difficult for me to find a job, but it has been suggested that I find a hobby to occupy my time. However, I am currently finding this difficult also, as I don't really know what fires my interests. I would appreciate it if you could give me ways in which I could expand and venture out into the big wide world as opposed to being a recluse and sitting on my XBOX, and watching DVDs all day which is my only real passion.

I'm not a physical person, and I don't enjoy exercise. However, I love all animals (we have three dogs), and I am approaching another college course. I've been in further education since I left school at 16. I do feel like the proverbial "fish out of water", and so for this reason I seek solitude in the safety of my own bedroom.

All suggestions, input, and advice would be greatly received.

Yours sincerely,

Sean

Atlantis creature

by DS Linney

(after watching films including the Abyss and reading too many fairytales)

DS Linney's art appears on the cover

Rainstorm — electricity —
brain wave — pulse rate — EEG
I listen to the frequencies, waves like heartbeats of the sea
I know the signal's travelling from where I want to be

The sound waves cause an avalanche
light wavelengths travel far —
and crashing rocks reverberate, reach tidal waves to where you are

A million years of patient search —
sifting what I saved
to crack the code, the formula to make the perfect wave.

So all the time, the answer's here —
a simple way, that seems
to generate an alpha wave, deliver all my dreams.

When mountains splinter down to sand
as after-shocks go through the land
upheavals change the shape of every shore,
so from the underwater cave
I'll come in on that perfect wave —
the one you never saw.

DS Linney would like to credit the Goth's editing of this poem, as she feels he has substantially improved it.

The rules of *Asperger United*

(contact information for *AU* is on page 2 and again on page 20)

- 1) *Asperger United* is funded by the NAS and readers' donations, and is independent of the NAS. Although it is called "*Asperger United*" it aims to cover the whole of the (reading) autism spectrum. That is, the concerns and joys of any subscriber on the spectrum can be printed, not just Asperger's.
- 2) Pieces that appear in *AU* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 3) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- 4) *AU* does not use your contact details for anything other than administering *AU*. Your details are not passed on to NAS Marketing, NAS Fundraising or any other organisation without your written permission.
- 5) If you move house, please inform *AU* and include your old address as well as your new address.
- 6) Even if you've paid for the Royal Mail forwarding service (or another forwarding service if you live outside Great Britain and Northern Ireland), you still need to inform *Asperger United* that you have moved address.
- 7) If you want to unsubscribe, inform *AU* and include your address.
- 8) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address.
- 9) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as sometimes the line isn't very clear. Please give any phone number you leave twice for the same reason. Remember to give your postal address so that we can find you in our records.
- 10) The current edition of *AU* is available at www.autism.org.uk/aspergerunited
You need to scroll down to near the bottom of the page, where there is a link to the PDF.
- 11) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 12) Book reviews are the most popular thing in *AU*, please consider submitting one. They can be about any book, not just books about autism. Also, they do not have to be short (the Goth keeps most of his reviews short to leave more space for other writers). If you do not want your review to appear in the NAS section of the Amazon website, please make this clear.
- 13) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.



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Family on the spectrum

by Paul

My Mother knew I was different from an early age. I didn't gain functional speech until I was 7 to 8 years old. I was in "my world" for many years and in some ways I still am. There was recognition of a diagnosis. I had worked loyally at a supermarket for over five years but had to leave because of the onset of depression and a mental breakdown. I went through mental health services and was misdiagnosed with "Asperger traits with a complex personality".

This didn't go down well with my parents nor me. I started attending a social group for people with autism. It has helped a great deal with my confidence. My father decided to come along. Slowly he began to notice that he was like many of the members. He had obsessions: his were weight training, collecting precious stones, one-sided conversations, problems in work and social gatherings. It all seemed to fit . . . and it did. :-)

Through the help of a local organisation my father was diagnosed with AS at age 49. How did he feel after the diagnostic appointment? Well, he felt relieved everything made sense for him. My mother and I were so pleased for him.

It was me next. I knew I was a different to my father in how my autism affected me. I got diagnosed with High-Functioning Autism at 24 years old. Not only did I have speech delay but I was classically autistic as a child and in many ways I still am. I was relieved. My father and I were autistic . . . could my mother be also?

My mother was the next person to get diagnosed at age 47. She was diagnosed with atypical autism. This again made a whole lot of sense to her. We all collectively found great relief for ourselves and each other. We have always looked out for each other and understood each other's needs — we do that even more so now!

With my grandfather well on the way to getting a diagnosis at 83 years old it makes us wonder how far back does this go in our family? It may make fellow readers think the same thing.

We're all positive and that positivity has helped us cope with everything in life. We're a strong unit: we help others and each other. The diagnosis has helped us understand why.

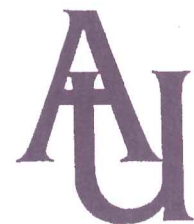
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