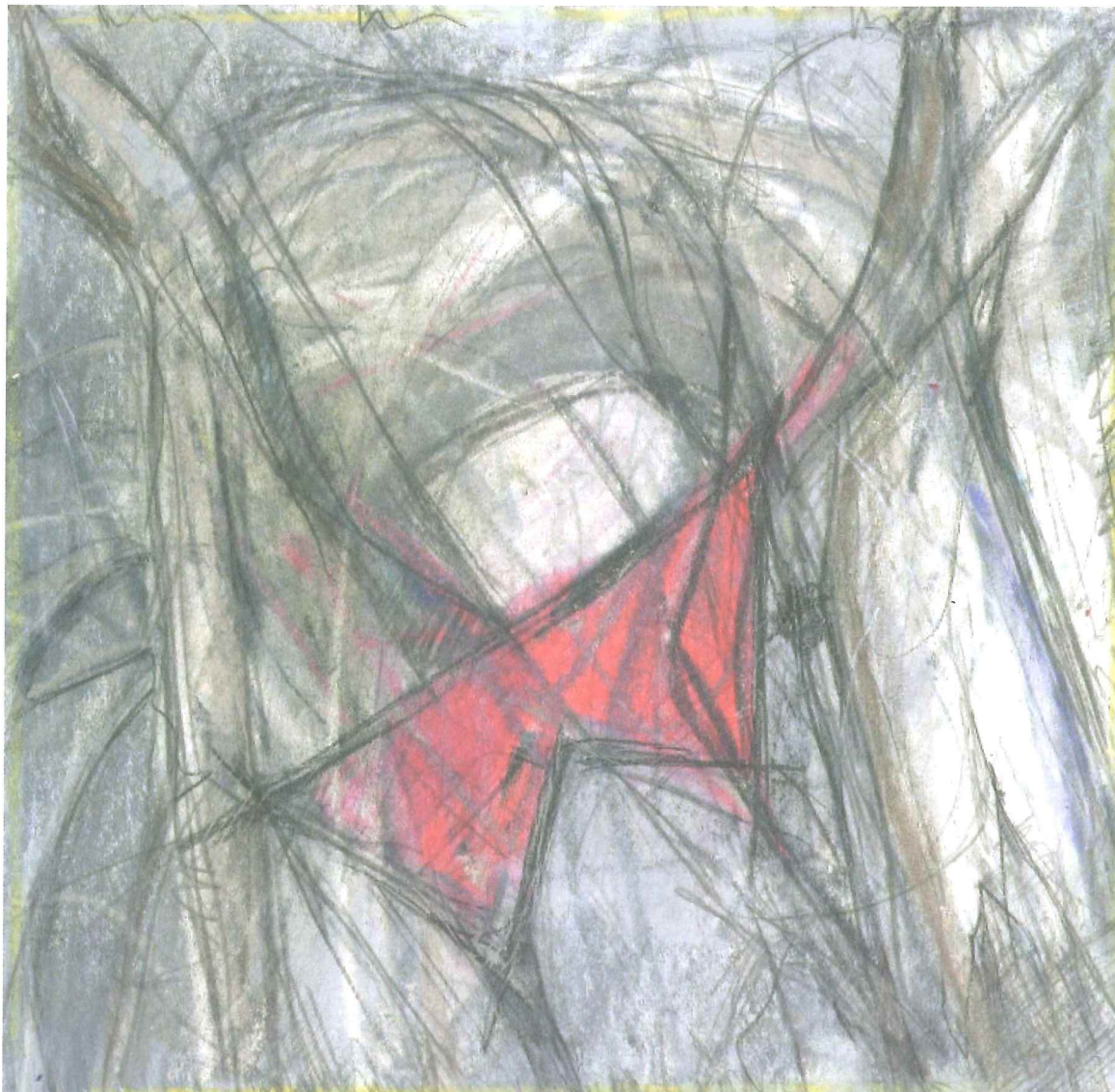


Produced by and for people who have autism-spectrum conditions

# Asperger *United*

Edition 68 October 2011

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# 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:**

*Asperger United*  
c/o The National Autistic Society  
393 City Road  
London EC1V 1NG  
Tel: 020 7903 3595  
Fax: 020 7833 9666

Email: [asp.utd@nas.org.uk](mailto: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.

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 **7 November '11**



**Welcome** to the October edition of *Asperger United*.

Several years ago (2007) I conducted a readership survey, and one of the results of this was that some people were interested in a gazette of social groups and other services being published in the magazine. With limited space, this hasn't yet happened, but I'm going to ask you for the information and once I've seen how much is sent in I'll decide what's best to do with it.

So, if you know of any adult group or adult service that you think should be mentioned in *AU*, please put contact details (the address for the group or service, a website address if it has one, and the organiser's name, address, e-mail and phone number) and a very short description

in a letter or e-mail. Please also include your own contact details. Check with the organiser of the group or service, so that they know what's happening and can confirm the details and description are correct, and say in your letter or email who you contacted.

Is it important to know whether the group or service is organised by the NAS? Should the NAS be providing more services? Or do you prefer your groups and services to be independent of the NAS?

As ever, I look forward to reading your letters on these and any other subjects, and I hope you enjoy this edition,

**the Editor**

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## Mental health

I have never thought that these two words belonged well together; my image of mental is the recollection that I have as I hovered over an application form, for the second time for an agency and after being iron-willed about my character of honesty, as a matter of personal pride and identification. I ticked NO, for the have you *ever* had a mental health condition; with such a broad sweep of language in the rest of the question that I was fully aware of just what a whopper this was going to be. One of Thatcher's millions they called me. The things they would dream up to control the outcome of the social opinions and struggle, *then* people were quite unafraid to gather together and make themselves known, as well as their cause.

"You have to lie, it's how things are"! This was to become the world as I had been told it never was.

I had to work; I could hear the echoes of her demand. "Oh what a tangled web we weave when first we practice to deceive"; it was like a bad psycho movie played out in my head along with all the other things that were attached to this one action flooding me, I could feel my head switch, muscles bracing, skin alarming, hearing becoming acute and a sensitivity was born. I felt my heart beating with a deep thud that had a strength different to the pump of the 800 metres, this was a banging that was driven with more force than I had known. This was adrenaline and the vulnerability of being in uncharted territory, other people and all strangers, alone that was nothing new. I betrayed myself for the first of many conscious times for choices that were not mine. I had no idea what was going to be thrown at me that day, but I left that office with no doubt that it was going to be unfriendly. The degree of which would wound and dismay, it astounds me today.

I was 17 and my dyslexia was so evident that I could not write three lines without an ink-pot

war on the page. Since then I have lived a lifetime of these moments and now the people around me have a name for the reason they treated me with the harshnesses that I so well remember.

I have come over the years to have the words to say that give a glimpse of the pain and fear that my journey has in its threads; a tapestry of life that I have fought to give a bright view to. I read all the latest self-help books I could in an effort to improve my lot. I began to harvest bits of the behaviours I saw and liked in the strangers around me, and it took me the longest time to learn the difference between the skills I liked and the ones that were good for me. That was not a happy day, not a celebration of discovery. You see when the rules change they alter so much of the stuff that has already been learned, the effect is massive when the knowledge is small but when the years go by and the visual compartmentalisation graduates from a bit detached, to a meltdown when interrupted, that is another matter.

I am fortunate that my "performing-bear-like responses", had been honed in the social advance of behaviour modification; reinforced, ripe and loaded after a three-year hike through the benefits of daily bullying and the demanded practice of "turning the other cheek". You can't hit people! The adventure of the mind this combination procures is another story, but forgetting seemed a far off contemplation I had not even dreamed of.

Since the *beginning* I have learned to stay safe! I cannot recall the things that I have closed my eyes to in the manner that I did that day with the form, when I could still get locked up just for being me. It was the years of the "frigid mother", that held all the connotations of "childhood schizophrenia"; "Munchausen mums" was a descriptor that had not yet aired at that time. I did not know it then but I would spend the rest of my



life running, running to or from so many things. I had more bad labels than a skip at the back of a clothing store and life had just got started.

Death was out — when you wake up in the recovery room for the third time at 21 and the first thing that comes into your mind: *that* experience, the sweetness of *slow* just for a moment, while you form the realisation “I’m still here”.

I put my simple and absolute survival into a driven execution of ego, brutality and preservation of: *my* view, *my* ideas, *my* choices and I began accepting; accepting the consequences, that was easy I did not have a problem with that one; humiliation as a friend, the kids on the bus had done me proud. So I began to weave and learn and fall often, hard, badly and eventually with pride and did I fall in spectacular fashion. I learned how I worked and why I did the things I did. “Don’t get so keen” this was no avenue to a cure just a better performance. I built a fortress of understanding in the wall and who I am behind that; don’t think you can swan on in and come up all rosy with understanding. You can’t.

Since those first days and the many gruelling ones before I built a world, I learned to do a great deal of things. The collection of City and Guilds, the driving licences, the civil partnership, the trips around the world; expeditions of desperation turned into beauty. Don’t let them fool you. My perception of my heart beat has never changed and I have betrayed myself so much I no longer know who I am. If I do not pause to grasp the flimsy hand-holds I have remaining, I drown in the crisis that quantifies my days. I have sold integrity for a meal. I am behind my mask. But I will find a way to make good and have the things I value even if it is only in my silence.

In the place of horrors I have mountains and lakes to remember, I have sunsets and sunrises of fire dancing and stars that move like fireflies. I hear the difference in the sound of rivers depending on the chill they run in; bears know what I look and sound like and have taught me my place in the world. For, I never knew fear till I heard the sound of a bear next to me in the bush.

## Health

That remains to be . . . The five stages of catatonia passed and turned, turned in and control, control like only an autistic can do, I have become a master and know intimately the threads that make up me. In this, the private clinic of my mind, I have health at my fingertips and just out of reach. “Crisis what crisis” as I venture into the uncharted territory, a cursory diagnosis; my own judgement confirmed and years of searching; pressed to the edge of brinkmanship, theirs and mine.

Normal; nor-mal without malady, not yet, you see; you are, still . . . not listening yet. Have you passed the annoyance stage, the indifference, the anger, the shame, the helplessness, I had to learn each one of these — turned and examined in an inner-world dynamic that the words to just begin describing cause clutched heads and whines of complication even in the learned among you.

I translate my experience into the language you are convinced you use “well”, while I tend to think I use it “accurately”. In as much as these are the words you gave me as tools of expression I was not the one who choose their form or meaning. Annoying again, huh! We share this journey.

I perceive and view from a monotropic cosmology and I know I can be “mentally healthy”. That is autism today; tomorrow it may just be another world view.

I can learn; I can discover: at 26 I discovered I was allowed to make mistakes; at 42 I began to assimilate disassociation, a part of my lifetime experience; at 47 I understood spontaneity — my translation was less than generous; at 48 I am tired.

And I will never forget that without understanding, autism inspires cruelty; but I survive and I have been called resilient and like thousands before me, I am working it out.

## Wolfbear

ASD. ComPTSD. Dyslexia. These are my credentials.

Hi Goth,

Hope all is well with you. Hope you like the poems. The poem, *Sing*, is about a woman I met. She is beautiful. I like her very much. Women and cider are my weaknesses.

Love

Daniel

## Sing

I'm looking for love  
I've found you  
But dare not say it  
It might come true  
I listen to your words  
In a tune  
And when you sing  
My heart does too

---

## Correction

Hello, my name is Rudy Simone and I was sent a copy of your magazine which contained a review of my book. A couple of corrections: the writer's statement that I wasn't diagnosed until my daughter was, was actually from Liane Holliday Willey's foreword. My daughter does not have Asperger's.

I interviewed women from the US, Canada, Europe and the UK, not just the states, as the writer contends.

I thank you for publishing the review, and it was positive, but of course, these two points are fairly important as they may be re-quoted around the Internet. I don't know if you print corrections, but please let the writer know, in case she reprints this article anywhere else.

Thank you,

Rudy Simone

## Aspies on mental health speaking for ourselves

edited by **Luke Beardon** and  
**Dean Worton**

ISBN: 978 1 84905 152 1

£14.99 / \$22.95

Jessica Kingsley Publishers

### review by the Goth

Another collection of essays collected and co-edited by Luke Beardon, this includes such varied stories, from the extremely bitter (Cornish) to the irrepressibly optimistic (Lynette), and covering a range of circumstances, so that I find it hard to imagine that you won't find someone's story, or more than one person's story, that has similarities to your own. I found several of the stories relevant to my own life and helpful in my understanding both of myself and of the situations — reading someone else's story gives you that bit of objectivity and so allows you to see the overall perspective more clearly. Well worth a read if you find such stories useful, though one to avoid if you're going to find some of them depressing.

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Dear AU

Is anyone interested in helping to establish a social group for adults with Asperger's syndrome or high-functioning autism in Worcestershire?

Email: [sarah@wits-endweb.co.uk](mailto:sarah@wits-endweb.co.uk)

Please telephone my mum, Julia, on

01562 754 727

if you need any further information.



# Pen pals

## Pen pal number 95

Hello, I'm Daniel. I'm 40 years old and have Asperger's.

I have lived independently since I was 23, but that has been achieved at the expense of my mental well-being and I do not lead a happy life. On the surface it doesn't look like there is a big problem with me, but inside I am struggling hard with life! I cannot talk about my real experience of life to most people, because they wouldn't understand or be interested. That makes me feel, as the saying goes, "lonely in a room full of people" and I'm fed up with it.

I would like to talk to caring, intelligent, honest people who understand Asperger's well and with whom I could talk openly.

My hobbies include cycling, walking in the countryside, and rational thinking.

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## Pen pal number 96

Hello,

my name is Karina. I live near Doncaster with my husband and children. I am 28 and I was diagnosed with AS a couple of months ago.

I have always wondered why it was so difficult for me to mix and make friends with people and now I have my answer. I do not have anybody that I have much in common with or whom I can just meet up with. I love music and singing, reading autobiographies. I would love to hear from somebody around my age group who would like a friend.

## 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 97

**My name is Eleanor** and I am 26 years old. I have very able autism and I live in a flat with staff support. I would like to write to preferably girls only around my own age who live in Somerset and who do not live in a care home. I want a friendship not a relationship as I have a close male friend and I do not want any more other than one close male friend. I do not mind male friends but not for a relationship.

My hobbies include: horticulture, animals, music, reading (non-fiction), cafés and walking. I can cook my own meals and I have GCSEs. I feel there are very few women the same sort of level as me and I would like to chat with other ladies.

### Pen pal number 98

**My name is Claire.** I am 28 years old in Warwickshire. I was diagnosed in 1994. I enjoy cross stitch and knitting. I haven't got a job currently but I do volunteer work in a charity shop. I would love to hear from anyone who has same interests and around my age. Thank you.

### Pen pal number 99

**49, diagnosed Asperger** ten years ago, live in Norfolk. Would like to hear from *other* adult Asperger's in our part of the country. *Interests:* autism/mental health issues, cats, arts and crafts, mythology, eg. *the Golden Bough*, and digital film-making and sound production.

Ephemerol 9

### Pen pal number 100

**Hello, my name is James,** am 32. I was diagnosed with autism in February which was a relief for me. I want more of a social life. Hope can meet people in the Newhaven area.

### Pen pal number 101

**Hi, my name is Harriet.** I am 21 years old and live in Northampton.

My interests are going to church, writing, playing computer games, filming, designing and being creative. My favourite colours are rainbow.

Don't mind who contacts me but am particularly looking for people with a similar age.

### Pen pal number 102

**Hi, my name is Reece.** I am from the East Midlands. I am 14 years old. I was diagnosed three years ago with Asperger's.

I would like to talk to someone who shares my interests and also would be interested to hear anything that would help me cope at school better. My interests include geography, ICT, computers, James Bond films, science, SGI and *Mythbusters*, and playing on my Xbox.

I would enjoy talking to anyone, no matter what the age.

### Pen pal number 103

**Hi, my name is Tony,** I am 39 and live in Derbyshire.

I consider myself spiritually aware and open-minded. I enjoy meditation, hiking and camping in the Peak District, and I am also a lover of nature.

I don't tend to watch much TV, I would rather be reading a book, mostly those mind, body, spirit sort. I also have a diverse taste in music; from heavy metal to Charlie Landsborough.

I would love to hear from anyone who feels they may like to be pen-friends.



## Pen pal number 104

Dear *Asperger United*,

my name is Matthew, I am 27 years old and I have recently read a book called *Autism spectrum disorders — the complete guide* by Chantal Sicile-Kira and I found it very interesting. Some of the information written in it is what my parents had to do with me when I was a child, that is, signs on doors to separate private from public, and

pointing me in the right direction when walking around the house naked, etc. Now I don't have signs on my bedroom door, underwear drawer, etc., as I now live independently and have a part-time job which I've held down for nearly five years. When I was 18 my parents didn't think I'd be doing that, so with the right support it goes to show how far ASD people can go in life and I would like to share with other ASD people by advertising in your *Asperger United* magazine.

If sufficient material is sent in, the theme for January will be **relationships**. Not just romantic relationships, but any sort of relationship, including one's relationship to anything and everything. If anyone's made a success of any sort of relationship, do let us know! 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!

## NAS Christmas cards 2011 and Christmas card design competition 2012

Christmas is coming and we have some great cards to choose from and in case you are spoilt for choice, we are again offering our bargain pack of fifteen of last year's most popular designs.

For more information and to place an order see the enclosed catalogue or visit:

[www.autism.org.uk/christmascards](http://www.autism.org.uk/christmascards)

Look out for last year's winning entry. There were many fantastic entries but Sarah's knitted design stood out.

The competition for adults on the autism spectrum to design a card for the NAS 2012 range is running again this year so why not put your artistry to the test?

Here are some points to remember:

- Your design should have a Christmas theme and be at least 210mm by 210mm (but it doesn't have to be square)

- Avoid using shiny colours and objects such as gold, silver and coloured foils in collage work as these are difficult to reproduce in print. Do not fold your design
- Please write your name, address and age on the reverse of your design with a suggested title
- You must be 18 or over to enter and we cannot return your entries
- The closing date is 12 February 2012

Send your design either by post to: Christmas Card Design Competition, The National Autistic Society, 393 City Road, London, EC1V 1NG

Or send your design and details in digital format by email to: [xmascards@nas.org.uk](mailto:xmascards@nas.org.uk)  
The resolution of your design must be 300dpi (dots per inch) or more.

Details are also available at  
[www.autism.org.uk/christmascardcompetition](http://www.autism.org.uk/christmascardcompetition)

## letter to the Editor and a poem

Dear AU,

I saw a beggar leaning on his wooden crutch,  
He said to me, "You must not ask for so much."  
And a pretty woman leaning in her darkened door,  
She cried to me, "Hey, why not ask for more?"

— Leonard Cohen song

I wish to write about disability and second-class citizenship. As I was a premature baby, my parents always knew that I had brain damage. Until I was 21 or so, however, I did not have an ASD diagnosis, so any kind of accommodations for it were hard to come by and were always "unofficial". As so many of us, I had a miserable time with peers in school, but I have fond memories of some teachers and especially of my Latin class when I was 14.

At 18, I left my parents to go off to attend college one hour away by aeroplane. At that time, my father had just remarried and I saw no way to stay with him. Additionally I thought my peers would miraculously turn into better people and that I would miraculously turn into a "normal" adult. However, as luck would have it, I came across some nasty people who harassed me to the point of me having a sort of nervous breakdown, which eventually resulted in my diagnosis.

My reason for writing is that I feel that my father is all too present in my life now that I am almost 30, even though we live ten hours apart in different countries. I felt a real drop in status coming into adulthood, a drop in freedom. I don't know what to call it: invasive parenting, helicopter parenting, remote parenting? But I really resent it, and I wonder if it is just a question of me being too weak or if others with ASD also have dysfunctional, toxic relationships with their parents? In my case, my father and other older adults haven't stopped thinking for me, projecting for me, eg. telling me I should stay at my job because I may never get another one. The latest problem — and the one that has pushed me to write this — is that he is pressuring me

to buy an apartment, which I am putting all my savings in and have to take out a massive loan for, which effectively prevents me from pursuing any of my dreams (or remaining free) and certainly doesn't make my life any simpler. I brought up the subject of not being able to follow through with something if I don't have my father's approval and a possible connection between this lack of independence and "executive functioning disorder" with a therapist.

Here is where the double standard comes in: I believe he is very afraid for my future, which keeps him from letting go of me. And he is not dominating over my ("normal") sister in the same way. Do other AS people also notice that people like to dominate us? Do other AS people also notice that people have lower expectations for us or expect us to have lower expectations for ourselves? Am I asking for too much?

Sincerely,

tighteningtork

"To keep your independence, the ego must never overtake the cash flow."

— L le Duff

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## Unsound mind

People are a-doing: busy all day  
I am not, that is my way.  
Used to be of unsound mind  
They were nothing of the kind.  
Used to be of unsound mind  
But now am not: isn't that a bind.

Peter



## The ARGH autism alert card

by Kabie

[www.arghighland.co.uk](http://www.arghighland.co.uk)

The ARGH Autism Alert Card is made by and for autistic people. It started as a membership card for ARGH members only. When ARGH started to get requests from people who weren't members — people out of area, young people under 18 and parents enquiring on behalf of their children — we realised that it wasn't fair for us to restrict access. People told us that they really liked the simple, uncluttered design of the card and the wording that they felt was more meaningful to them than that found on other cards.

We decided that keeping the card just for members, or asking everyone who wanted a card to become a member, wasn't a good idea, so instead we made a new version of the card available to everyone, regardless of age and regardless of where they live. It costs £1.

Our intention is that it can be used in all areas of society, shops, libraries, and so on: not just with emergency-type situations. Made in a credit-card style from high-quality plastic, the alert card fits easily into a person's wallet, purse or pocket. Designed to be easy to carry, it acts as a visual aid to assist both the person carrying it and the person to whom it is presented.

The card is now carried and recognised by people across the UK including Northern Ireland, Scotland, England and Wales (and a few internationally).

### What is ARGH?

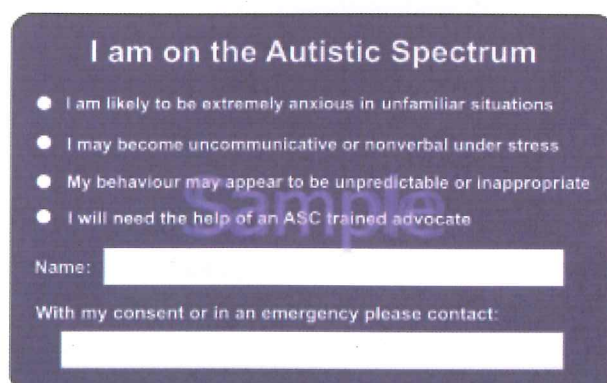
ARGH is run by and for autistic adults, independent, we are self-governing and self-funding; a group controlled by autistic people to promote the rights of autistic people.

We want to show people that autistic adults are autonomous; we want to speak for ourselves and we want to change the presumption that we need others to speak for us.

We feel that coming together as a collective makes many individual voices stronger; one person's weaknesses are overcome by another's strengths; we believe that everyone has something unique to offer and something to gain by working in this way. These are principles that we want to see reflected in wider society.

Through training we inform service providers about what autistic people really experience.

We hold meetings for members, produce a newsletter, campaign for improved services and challenge discrimination as a group and as individuals in our daily lives. "Nothing About Us Without Us" is really important to us because all too often we feel that people do things "for" and "to" us rather than allowing us to take the lead and live our lives in the way we choose.



## Dear Goth

I agree with the writer who says every edition is getting more splendid. I take that as a sign we are all getting more splendid — readers, contributors and the Editor! [this is meant as a compliment]. I love the colour, new layout and brown text [I hope it is brown, not my eyesight?]. A “wish” would be cream paper but that would be more expensive.

Thanks to John for the background colour settings for cream. Would it be an idea to have a column where people ask technical or other questions, then let readers answer them in the next edition? I have seen such a thing in national newspapers. We are a bunch of experts after all!

I enjoyed the Atlantis poem, particularly “When mountains splinter down to sand”. Wow, what a powerful line. It fills me with a sense of timelessness and is very comforting.

I am sorry non-computer users feel left out. I used to hate computers because the man I married [and wish I hadn’t] was a computer expert. However, when I got rid of him [divorce, not murder!] I was curious about computers, tried it and liked it. I used the software Word to write letters, then gradually learned Microsoft Office. Once you have learned one package, the others are similar. Please don’t be put off by computers! There are many courses and books for beginners [eg. Dummies guides are excellent with sample pictures of what you see on the screen]. This knowledge does not come overnight but you learn bit by bit, by trial and error. I wrote this article about my writing.

I agree with readers about clothing being uncomfortable. I only buy soft materials. I change into pyjamas after work, and on days off sometimes stay in these all day after my shower. I find bras uncomfortable but necessary for physical comfort [lady readers know this!].

By the way, hoorah for John on having his letter published! It feels great to be published, doesn’t it!

Marianne

## The joy of text

I love to write. I started writing age 10 and used to walk twenty minutes so I could write in the local cemetery where it was peaceful. The park was too noisy for me. The gravediggers got to know me and never bothered me even if there were funerals on. I love being in cemeteries even now in my fifties.

I write every day. I am a published author and working on my first screenplay. Writing is a huge part of my life and I write for pleasure as well as potential profit. It is hard to earn money by writing but that does not matter to me as I enjoy the craft. I write all sorts — non-fiction, poetry, journals, articles, a screenplay, letters, diaries. I will describe some below.

I enjoy writing poetry. I belong to a poetry group. We write to a subject each month and read poems we have enjoyed. We don’t criticise our poems, just enjoy them. There are informal poetry and writers groups in many towns and I’ve belonged to a lot. It is free and you meet like-minded people without having the difficulties of intimacy and complicated friendships. Poetry is different to text and can be learned by reading and listening to other poems.

I write three pages a day in a day journal [this is an exercise from the excellent book *The artist’s way* by Julia Cameron]. This exercise aims at ridding yourself of rubbish self talk, eg. “I feel really bad today. It’s raining.” etc.]. You aim to get out the bad things so you can be more creative in the other areas of writing!

I recently started a new hard-back diary in which I write only positive experiences — this is much shorter but I try very hard to do it every day. For example, I write about nice things that happen — if I have seen a rainbow or an otter, if I have baked or written something I am pleased about, or if I have enjoyed a particularly good conversation. Life moves so quickly these small happinesses are easily overlooked or forgotten. I am inspired by re-reading this diary if I feel



down. The best thing so far is seeing the otter as they are very shy creatures!

My other journal project is *Book of inspiration* where I write my wishes for the future — this one is indexed, eg. health, home, hobbies. I hand-write this as it is very special to me. I do not write in this every day, but only when inspired.

Two of my other “special interests” connected with creativity are compiling databases and making slideshows or collages from my photographs. I spend many happy hours doing these things, just for fun.

About publishing. I am professionally published with three books in print at one time. But it is now easy for anyone to publish informally [ie. for your own use, without an ISBN] because of POD [print on demand]. You can have a single book published with, for example, your recipes, photographs, poems or self-designed calendar. It costs as little as £5. For example, you can design and print your own colour recipe book with images of your own baking and cooking. There is a lot of fun to be had with computers and writing. I am making my own recipe cards which are nicer to use than a pre-written text by someone else.

Life is not all black with Asperger's. If you have a lot of time to spend alone because of social difficulties, you may as well find something creative which gives you pleasure. People are often very jealous about the amount of “free” time I have — but they don't know about the loneliness, lack of money or not-so-good housing I have gone through to reach this point. Now, I covet my free time.

I don't have much money — but who knows! Anyone know an entrepreneur who wants a screenwriter?! I spend my time, when not working to earn money, researching, writing, polishing and enjoying text and images. I also enjoy listening to music and am learning how to paint in gouache. It is an individual lifestyle, of which work is a part but not the main outlet.

## Nottingham Aspies

**Matthew McVeagh**

organiser of Nottingham Aspies

Nottingham Aspies is a group for adults with Asperger's syndrome living in the Nottingham area. We have five aims:

- (1) to organise ourselves independently
- (2) to help each other
- (3) to collect useful information on our condition
- (4) to represent Aspies locally
- (5) to campaign for better understanding and treatment.

We have various activities both happening and planned including regular meetings, internet development, socialising, discussion of issues, advice and support, trips, education and self-improvement.

General meetings are open to people over 18 with AS in or near Nottingham. By arrangement we can include carers, support workers and such where appropriate, and we may invite non-Aspies to attend, for example to give talks. We are also planning some more specific events. In the first instance get in touch via

**nottmaspselfhelp@gmail.com**

or phone Self Help Nottingham on **0115 911 1662** to have a message passed on to us.

We look forward to meeting you!

## Dear Goth

I wrote the following short essay in 2009. At the time I hadn't even heard of Asperger syndrome, let alone considered I may be on the spectrum. I am now pretty sure I am an "Aspie".

Looking back over my life, so much of it makes sense now given the perspective of Asperger's. I have always felt like I was from a different planet. Looking in on a world I was not able to be a part of.

I would really appreciate it if you would consider printing my words in your wonderful publication *AU*.

Kind regards

Sarah

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## Of another world

by Penelope

I am of another world —  
A visitor, a stranger to your shores,  
An immigrant born in your heartland.  
I am other,  
Apart,  
A legal alien in native skin,  
Vulnerable,  
At your mercy.  
So treat me gently:  
Your customs are strange to me,  
Although I was raised within them,  
And I fear your people,  
Your places,  
You.  
Accept my behaviours,  
As I accept yours,  
And understand that I am different,  
Not dangerous;  
I shall come to love your world;  
And it shall become my home from home;  
But at heart,  
I am always other,  
Always apart.  
I am of another world.

## Wrong planet syndrome

I know my origins are elsewhere and I must have a purpose for being here but I long to be returned to my home. I see opportunities in the sky but they pass by too far to hear me. Too distant to sense that I am waiting. Unaware that I am in need of assistance, of help to move on, to understand why I am here and what I should be doing.

I am increasingly aware that I see things differently to other people. I notice things they seem blind to. Nuances in life seem to pass others by, where as I am subjected to an overload of feelings and images. Even my dreams are like waking in their vividity. And it hurts. I long for the ignorance, the lack of subtlety that plagues the human world. A release and an end to this bombardment.

But do I? Maybe not. Maybe it is better to be aware. The subtleties in life need to be appreciated, not ignored. Enjoyed not dismissed. I have a gift, perhaps. I should embrace it and be strong. If I can.

So, it seems, the longer I remain here, the more confused I get by the human race. And the more sensitive I am becoming to it. It is difficult to remain without wanting to hide away, to cut myself off from the chaos that pervades all corners of the Earth in this time.

I know I am not alone on this world, though it feels like I am so much of the time. There are others like me. We may be legion. I hope we are.

As far away as it may be, in time and in space, I still hope for the chance to go home.



## Asperger's and anorexia

by Sian

I'm a twenty-four-year-old female, diagnosed last year with AS, and for me both Asperger's and mental health have had a huge impact on my life.

How many of us Aspies have grown up listening to phrases such as "you should be able to do that" or "that was rude"? How many of us have found that, no matter what we do, we always seem to make mistakes and be in the wrong, without even understanding what we've done.

Growing up in this way, it can lead to feeling as though we are "wrong" or "defective", and for me that led to low self-esteem and depression, as well as an intense need to find a way to improve myself and make myself acceptable to others.

Not knowing that Asperger's was the explanation for my social mistakes, I looked for what could make people like me more. I heard lots of people talking about thin people being popular, and my literal Aspie brain believed that the thinner someone was, the more friends they would have. I cut out almost all food, and sat back, waiting for the friends to start turning up.

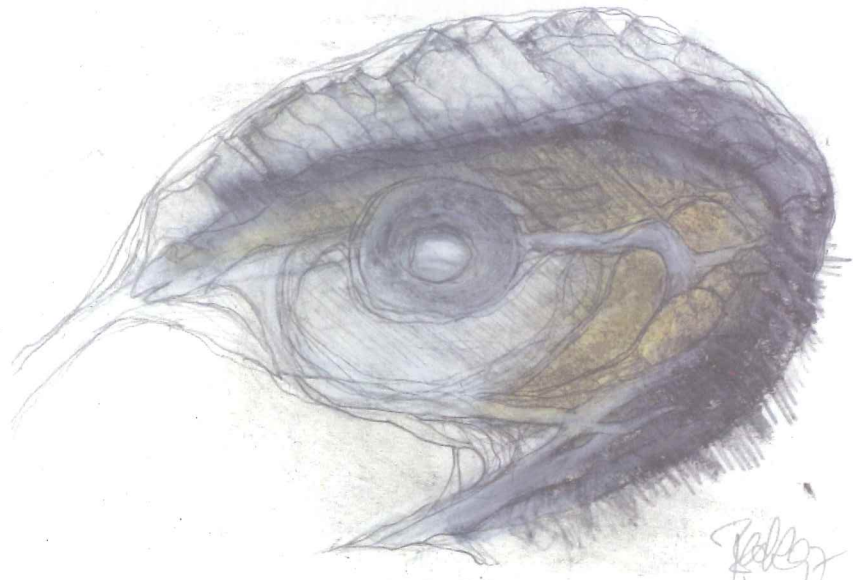
Even though it didn't work in the way I'd expected, the eating disorder still had its advantages. Eating exactly the same thing each day provided structure and routine, and the starvation shut down parts of my brain, meaning that the extreme anxiety I lived with as part of my Asperger's was dulled.

Of course, an eating disorder is *not* a good

idea, and it also made me very sick. I had almost no energy, and so my limited social life became even smaller. The headaches, stomach aches and dizziness were also not fun, but with my Asperger's still undiagnosed I believed that I deserved all of it.

A breakthrough came last year, when I was encouraged to get a diagnosis, and it really was a turning point. Suddenly I could understand that the difficulties I'd lived with my entire life weren't my fault, and that I wasn't a bad person. The years of depression, cutting, starving and being sick were a reaction to a confused and anxious mind, trying to cope with being Aspie in an NT world.

I still struggle with anxiety, and I'm only slowly learning to accept my differences, but diagnosis has made the change that I needed. If only I'd been diagnosed earlier, perhaps I wouldn't have struggled through so many mental health issues, or at least I'd have had the knowledge and support to deal with them in a better way.



## A different day

by Vincent

Casey walked to the edge of the playground alone. She placed her kit bag on the floor and sat down beside it. Casey had one really good friend at school, her classmate Brenda, but she had to go to the dentist and Casey would not see her till tomorrow, so Casey was spending her lunch break alone.

Casey didn't understand why people behaved the way they did or talked to each other the way they did. She just didn't understand people. Tears ran down Casey's freckled cheeks. She sniffed and looked at the pebbles on the ground. Casey loved to count pebbles and observe their different shapes and colours.

Her favourite was a bluish, small stone that sat away from the rest. She liked it so much because her favourite colour was blue.

Casey picked it up in her hands and held it in her palm, looking at every detail. She looked out across the playground; the people chattering reminded Casey of birds in a tree, chattering to each other. Chatter-chatter! Casey giggled to herself at the thought.

Casey sighed, returning her eyes to the pebbles on the ground. She tried looking at a larger black one, one of the biggest there, but Casey began to feel frightened — she was afraid of the dark — and had to turn her gaze to another stone.

She looked at a smaller grey stone, but that reminded her of boredom, and Casey was also reminded of maths.

Casey hated maths.

She looked at her blue stone again, and that reminded Casey of herself, sitting alone, away from the rest. Casey rubbed it. It had not

changed in the past minutes. It was still ridged and pocked like an asteroid, or a moon rock.

Casey set it down, but this time she accidentally placed it among the rest. A sense of panic hit Casey. She started to cry in frustration, and tried vainly to correct her mistake, but she could not remember where the blue pebble's exact place was. And all the other pebbles were in disarray, too.

This made her even more frustrated. Casey cried in a blind rage. She pushed the pebbles to one side angrily, sitting back on the bank and moving away from the pebbles. She kicked out with her feet, thrashing her arms like hammers.

Two other students, Kate and Annabelle, were attracted by Casey's outburst, and came over. Kate, the bigger of the two girls, pushed her foot into Casey's kit bag and said aggressively, "What's up with you, retard?"

Casey replied, "My pebbles are messed up."

"Pebbles, you idiot, what's wrong with you?" shouted Annabelle.

"There's nothing wrong with me," replied Casey defiantly. "I get upset about certain things."

Annabelle kicked the pebbles, sending them everywhere. Casey squealed, jumping up from the ground, trying to shield the pebbles with her arms.

"You're stupid, Casey!" Annabelle yelled, hitting her hard. Casey shrieked. Kate grabbed Casey by the shirt collar, kicking her in the back and sending her sprawling onto the ground face-first. Casey's nose hit the concrete and there was a cut on her cheek. Casey wailed in pain and anger.



Kate and Annabelle ran away, laughing, leaving poor Casey alone and hurt.

She lay sniffing on the ground, looking at her hand, which was also cut and bleeding.

Casey got up and sobbing she walked toward her kitbag.

"Casey!"

Casey looked up, not really wanting to see who was calling her. It was Miss Sorrento, a relatively new teacher at the school.

"Casey . . . Dent, is it?" she asked.

Casey nodded, wiping her tear stained face, still upset. "Yeah, that's me. Casey Dent," Casey replied sullenly.

"Aw. What a pretty name," Miss Sorrento said, smiling. "Casey, Holly Jones told me what Kate Drescher and Annabelle Seldon did to you. That was really mean of them."

Casey began to cry again. "I want my mum," she mumbled.

"Come on, then, Casey," Miss Sorrento smiled. "We need to speak to the headmistress about this bullying. It's going to stop, okay?"

Casey nodded, feeling a little better. "Okay."

When Casey entered the head teacher's office her mum was already there and so were two other people Casey had never seen before.

"Casey, this is Dr Sands; she's a specialist from the hospital and this is Mr Layton, our educational psychologist," said the head teacher, Mrs Banks. Casey was a little confused, but sat down next to her mum.

Dr Sands explained to Casey that she had been monitoring Casey, and after speaking with Mr Layton, they thought that Casey may have a form of autism called Asperger syndrome, but

Mr Layton would like to see Casey outside of school so that he could perform tests with her.

Casey frowned. "Asperger syndrome? What's that?"

Dr Sands explained to Casey all the aspects of the Asperger syndrome, and it all began to make sense to Casey, why she felt the ways she did, why she couldn't understand people's behaviour sometimes, why she felt the need to have structure and unerring routine.

Casey's mum held her hand and asked her, "How do you feel, lovely? Are you alright?"

Casey looked to Dr Sands. "Is this why I'm so good at drawing?" She liked to draw; every second of her home life was taken up with a paper and pencil. "And why I hate maths? And loud noises? And weird smells?" She smiled and let out a giggle.

Dr Sands replied, "Well, Casey, if you didn't have Asperger syndrome, there's a chance that you wouldn't be able to draw like you do. You might not be so great at English and history, like your teachers and Mr Layton tell me you are."

Casey felt happy for the first time that she could remember. "Thank you."

Mrs Banks then said that the bullying Casey endured would be dealt with, that awareness of her condition would be raised in the school with the help of Dr Sands, and that Casey would receive the right support in class.

Casey looked to her mum. "Mum, can we go to the library and get some books on Asp . . . ?" she asked, struggling with the last part.

"Asperger syndrome," her mum said. "Sure, Casey. You like the library anyway, don't you?"

As Casey and her mum left the school, Casey looked up at her mum and said, "Tomorrow's going to be a very different day, isn't it?"

Dear AU,

three cheers for Elkie for highlighting that the oft-held view about autistic people and computers does *not* apply to all of us. I'm in the same situation as Elkie in that I cannot use my academic skills and training not because of poor social communication but a lack of competence with computers.

Over the years I have tried and repeatedly failed to gain basic computer skills and now find myself unemployed. The terms used with computers are extremely confusing. Just holding a computer mouse makes me terribly agitated as my mind associates "mouse" with something alive, warm and furry but my hand is touching something cold, plastic and hard. My problems with modern technology have been far the most handicapping of my autistic traits and as websites become the normal form of getting information, I'm stuck with everything from getting train times to applying for jobs. I'm only in my thirties and I'm increasingly concerned about how I'll manage as computer competency becomes the norm.

I am also deeply concerned about ASD children who may be academically able but struggle with technology. I excelled at school and university but it would have been a torture if I'd been forced to use a computer, focus on an interactive whiteboard or listen to that awful, ear-shattering electric hum. We need to be robust about identifying these children and finding ways of educating them and allowing them to reach their full potential.

**Anonymous**

*Name and address were supplied to AU.*

## **Autism and the edges of the known world**

**Sensitivities, language and constructed reality**

**by Olga Bogdashina**

ISBN: 978 1 84905 042 5

£13.99 / \$19.95

Jessica Kingsley Publishers

**review by the Goth**

Olga Bogdashina beautifully presents the case for autism being, essentially, a difference in the way we process sensory information. She clearly makes the point that if you don't understand what someone is experiencing, then you can't make a fair judgment on whether their behaviour is reasonable.

The book goes on to consider and explore some of the consequences of extreme hypersensitivity, such as being able to pick up on the subtlest of body language cues. Such sensitivity can lead to apparent telepathy, for example, if the autist always seems to know when you're going out minutes before you start to get ready. Bogdashina takes the bold step of redefining "psychic" to refer to all such phenomena, regardless of the explanation for the abilities. As she recounts, her choice here has already brought on her a lot of criticism, and I must admit I don't see what she hopes to achieve by such an iconoclastic stance. Nevertheless, it is refreshing to read a book where an academic freely speaks her mind, and this is a valuable book to have towards the ongoing explanation of what autism is and how to see the world through our eyes.

*This book and the one on page 6 are available from all good bookshops and through Amazon's charitable scheme at*

**[www.autism.org.uk/shop/amazon-store.aspx](http://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.*



## 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.
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- 10) The current edition of AU is available at [www.autism.org.uk/aspergerunited](http://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 *Asperger United*, 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.



Dear AU,

After reading Edition 67 and seeing that you were considering talking about mental health, I wanted to send you in my poem that I wrote about having a meltdown. I am a 32-year-old "Aspermum" with four children, one of whom is diagnosed with AS, and I find that most people do not realise that there is anything unusual about me. But I wanted to make a point that for myself (and I believe for many women with AS) this is not due to the fact that we do not suffer from the negative AS symptoms, but just that we internalise them and I find I spend most of my life acting, pretending to be just like all the other mums. In my case, this usually results in a major build up and a total meltdown. I wrote this poem in a rush as I stood on the edge of one of these episodes, and think that it explains a side of my mind that even I would not have been able to describe when I am well.

Thanks,

Helen

## The meltdown

Like a mad dog, there's a crazy animal inside my mind  
Trying to snarl and snap and bite in every direction.  
It's thrashing about, trying to destroy everything and  
scream at everyone.

I hold it tight on its chain, but it pulls and pulls to the  
edges of my mind  
Trying to break out — to reveal itself to everyone else  
around me.  
Holding it back is tiring, so draining.

And all the while that I won't set it free  
It ravages away inside my head instead.

If I gave up and let go it would show the world my autism.  
I would hold my head and rock and scream and cry.  
But I'm a wife, a mother so I must fight it —  
I have to be strong and try.

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