

Produced by and for people who have autism-spectrum conditions

Asperger *United*

Edition **80** October 2014



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 who have 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. Discussions on editorial choices will not be entered into. *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 £9 per year from overseas readers and £15 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

National Autistic Society production support: the Publications Team

NAS phone support: the Supporter Care Team

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 Kaczynski, formerly Cohen.

Please send all correspondence and subscription requests to:

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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 magazine.

Asperger United is available in **large print** on A3 sheets (double the size of this page). If you need large print, please let us know using the postal or email address above.

Contributions for the next issue should reach *AU* by **1 November 2014**

Welcome to the October edition of *Asperger United*.

Last issue I suggested relationships as a theme, as it was clearly a topic which people had some things to say about. Then I realised it's only been nine months since the last relationships issue, so, to avoid confusion, I've decided to call this the empathy edition, as that is also a link between most of the contributions.

It was good to meet so many of you at Autscape again this year, along with some new

faces: it seems very appropriate that the report on the conference appears in this issue, as a great deal of empathy was on display, making for a very relaxed and enjoyable time.

For those of you in the London area (which is about a third of you), I hope the back page of the magazine will be of interest, as, after much delay, I'm looking for an assistant, and I'm looking forward to sorting through the applications along with all your other post and e-mail,

the Editor

the empathy edition — the next issue notice is on page 14

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Why I am single

by Tim

There are many reasons why, and most Asperger's/high-functioning autistics are single, yet very few, if not a single reason, very complex yet very simple: communication disorder. I suppose personal relationships can, in all honesty, be difficult even in non-Aspergics, so here I will try to explain why I think it is, after my many attempts at personal relationships, girlfriends.

I'm a so-called middle-aged Asperger man, in his mid fifties. At any age, it is very unlikely, and by now especially, regards: kids, children. I'm too old, I'm sure. To be honest, I could not have coped and in any case, with the possibility of genetically passing on the autism; I do wonder if in any case, as a matter of public policy, if there shouldn't be a selective mandatory sterilisation of all people with serious genetic anomalies, as there was even managed in a democracy, in the United States, state of North Carolina — my honest, considered opinion to prevent further suffering.

I've reckoned that since school and at school and college. Young ladies told me to get lost (to put it politely) if I requested a dance at a school disco. It is known that in all probability Aspergics do not "transmit"/pick-up the very subtle signals in the complex mating game, messages between themselves and potential suitors (lacking subtle "non-verbal" communication). (We know what sort of disability autism/Asperger's is.) And that's a fundamental difference between so-called "normal" people and Aspergics, though "the mating game" can even be frustrating for so-called "normal people", as well as probably all other species as well as *Homo sapiens* — for potential procreation, continuing of the species — but if I continued, I would make an encyclopaedia [on Darwin, and so on], so I'll continue, thusly:

My attempts to be married came to naught. I've been on various arranged dates as one or two

friends (who were non-Asperger's/non-autistic) have tried to help, including a Spanish young lady when I was in my thirties (in the 1990s) whom I took to the Ideal Home Exhibition, and a body, soul and mind exhibition, and an Iranian young lady on a date at Greenwich. Though my attitude was very traditionally gentlemanly and I tried very hard not to be self-centred, it didn't appeal much as I got later feedback from my friends that I was self-centred. Most probably, I was far too intense — I was nervous. I know/ we all know about autistics and their obsessions, self-centredness, talking *at* others not *with*, and so on. I am quite certain that it is to do with "subtle, non-verbal" signal-reading, as I said earlier.

It certainly didn't end in relationship, marriage, partnership! There's still social pressures even in this "day and age" to be married, have a partner. I was told, though, by family I may well be better off single as in fact the emotions and so on could be very difficult to cope with, and it really would be a mistake to try at being married/partnering just for the sake of struggling to be "like other people". I cannot logically conclude it would be real love.

Empathy, as said earlier in this article, is difficult for reasons I will repeat. One or two members of my friends and family have noted that, "It is very sad, though he has done very well, considering. It is very sad he's extremely unlikely to marry/fall in love, but you never know." I've known one or two Asperger's (a tiny, tiny minority) who have been "successful", which includes as above. I don't intend any more arranged dates, via friends or commercially, as that would smack of desperation and conclude I could be better off single as we all know about Asperger's.

I've wished I wasn't autistic but nevertheless that is what I am.

Autism and relationships

by Christopher

My name is Christopher and I am 46 years old. I was diagnosed with autistic features at age 2, and Asperger syndrome in my mid teens. I am happily married to Claudia (who is non-autistic). I live with my wife in South London.

The subject of relationships for people on the autistic spectrum is one of the, I would say, trickiest subjects to broach for all sorts of reasons. The relationships I have with the various members of my family are very differing from one to the next. For autistics, other people are often their biggest challenge, as everyone is different. My relationships reflect that.

As far as I know, it is unusual for an autistic to be married at all, let alone happily. We met online in 2003 and got married in 2007. The key to our relationship was telling Claudia about my autism early on. It meant that she started to understand me straight away and it explained any quirky behaviour that might have put her off if she hadn't known. Sometimes there are confusions of course. Maybe I forget she doesn't know everything I'm thinking and that an answer to a question she's asked is actually required. Or I forget that even if I get her a present, it's also usual to give your wife a card on her birthday.

I got on well with my wife's parents as soon as I met them and their support of us as a couple has been a very positive influence. The past few years have been tough as I was made redundant in 2009. I struggled to find a suitable job, not surprising given the dwindling number of jobs that are genuinely suitable for someone on the spectrum. So a year ago Claudia and I decided to start our own craft business which means that Claudia can help me at work as well as at home. It might not work for everyone but for us it is the perfect solution.

Before I began to live with Claudia, I lived with my mum. I liked living with her, even though it seemed that we kept ourselves separate as she often had friends round. I usually stayed in my room rather than trying to socialise. My late stepfather was a very sociable man too and I'm not sure that either of them completely understood why I preferred to be on my own. My relationship with my biological father is non-existent. We never really got on with each other and I haven't seen him since 1995. I now hope he is living a good life somewhere.

When we were young, my brother and I were the bitterest of rivals because he hated losing to me whether we were playing board games, playground games or sport. He also had trouble with me getting all the attention because of my autism, and winning helped him with his confidence. But since leaving school our relationship has really grown, although I don't see him or his family as much as I'd like to now as they are very busy.

Friendships are hard for me to develop, as they are for most people on the autistic spectrum. Most of the people I think of as friends are actually the friends of my wife and family. I used to think of my late stepfather as my best friend but, of course, to him I was a son. I do get on well with people at church but I don't have anyone that I would go out for a drink with, for example, unless Claudia and I were there as a couple. I've made some friends on social media, which is where I think most autistics have what they think of as a social life.

Finally, my relationship with autism itself. It has been a love-hate relationship, and I think that may be true of most people on the spectrum. But autism is part of me, and I have grown to be happy with autism, which in turn means I am now more at peace with myself than I was when I was younger.

Thoughts on Autscope

by Amanda

Imagine a world in which, when you are told your child has autism, instead of being given a list of what's "wrong" with them, and how life will always be a struggle, and how they will never "recover", and how it's unlikely they will be able to form and keep relationships What if, instead, you were told that yes, your child is neurologically atypical. And it will be hard, and you will all learn many lessons along the way. But that it will be okay.

That's the biggest thing Autscope said to me this year — it will all be okay.

In a miniature world where I had a typically atypical brain (meaning most other people were also autistic), I didn't feel disabled. It was structured, calm, and egos and judgment were absent. I met people easily as emotionally sensitive as I am that share my view that if anything, we are *more* emotionally connected to the world around us than non-autistic people are (I am generalising). I had to laugh when, in a workshop attempting to pathologise neurotypicality for use as a comparison, many people strongly opposed pathologising it. It seems they did not wish to make anyone feel ashamed or disordered because they did not have that right . . . when in fact, it's what non-autistic

people do to autistic people all the time. Who has more empathy here?

There is a community of autistic adults and they are being empowered by being in that community, and it matters to me that this community is working to change perceptions of autism. Autscope is a microcosm of what the larger autistic community could be: where views are debated and friendships forged and people encouraged to be themselves in a world that is always trying to force conformity. At Autscope people stim. They talk if they want to and don't if they don't. They hug if they want to and don't if they don't. They are quiet in the corridors. They look at the initiation badges before they speak. Difference is accommodated without scrutiny of *why*.

The autistic community at Autscope is every bit as loving and caring as any non-autistic community I have ever encountered, only perhaps more so. It makes me smile on the inside when I see that community no longer willing to take any kind of discrimination lying down. I smile when I see that there's a community that's ever-growing, willing to accept new members, that will welcome little autistic people and show them that they are not wrong. And that it will all be okay.

My first relationship was going great. I wanted him to get to know me and not the person with Asperger's. So I didn't tell him, at least not at first. Then, when I did, he dumped me for not being open up front. I now tell people up front and leave it up to them as to what happens next. I can't keep a job as I misread what people say to me. Does make me wonder how they would be if they didn't know. I have experience of people who didn't know I had AS, then they found out and started treating me like I'm an idiot. I am the only one in my family that

is autistic and I have always wondered why. It's not just other people that treat me like an idiot: my parents do. I have two sisters and I am not the youngest and I am an adult, but my parents treat me like a child. I have a boyfriend and he has let me down a few times: I have forgiven him but my family haven't; they don't like him; he also has learning needs, as they well know. The excuses to not like him are pathetic but my parents have always done this to me.

Claire

Pen pals

Pen pal number 181

Hi, my name is Victor. I am 17 years old. I don't speak English, but my mother speaks and she is my translator. I am from Brazil, so I speak Portuguese. But, I would like to have a pen pal from anywhere in the world. So, as I've received this magazine as a gift, I decided to participate on this . . . I live in Fortaleza, Ceara, and it's near to the beach. We have wonderful weather down here . . . My interests are: history, literature, arts, cinema, theatre, religious principles, and many others. I work as a volunteer at an elementary school, giving lectures, telling stories and some jokes to the children. I love doing this and they also enjoy themselves. I also give them presents when they get the answers to my questions, and they are usually books! Let's talk about any subject because talking to different people is a good way to learn about weird customs too!

A hug,

Victor

Pen pal number 182

Hi, my name is Connor. I'm 11 years old and I live Oldham county in Kentucky (United States). I have three dogs: Tucker, Buddy and Bear (one's a puppy). I love to play on my dad's XBox 360.

Also, Legos are my favorite toys. I do have autism if you're wondering. I hope to hear from you soon.

Connor

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.
- > Please note that *AU* does not print dating adverts, as it is unable to provide suitable support.
- > Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.

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.)
- > Please remember to put your address on your letter.
- > To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London, EC1V 1NG, or email asp.utd@nas.org.uk
- > 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.

****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 183

My name is Jack and I have Asperger's and OCD. Does anyone out there like the cinema? I love films and going to my local cinema in London. Sadly my best friend died. We enjoyed many years of cinema-going: it's not the same on your own. We used to take turns to choose, so I am not that rigid as to what I see.

I also like exhibitions, travel and eating out, usually before the cinema. My favourite films are *Duel*, *The wicker man*, *Poltergeist*, and all the *King Kongs*, but also comedy, anything really. I am an artist and printmaker and recently I have been exhibiting and selling work. My illustration was on the cover of an *AU*.

If you want to chat about films or go to the cinema let me know. You can see my artwork on tidydown.tumblr.com

I don't mind if you are male or female.

Thanks x

Pen pal number 184

My name is Becky. I am nearly 30 and I live in a care home for people with Asperger's. I put a pen-pal advert in *AU* before, asking if people were interested in the postal system and lyric-writing but not many people were interested and those who were didn't take interest in writing to me for very long. Would anyone like to write to me regularly purely about the phone system? I've written pen-pal adverts before about the postal system and lyric-writing but that got me nowhere, and I'm also highly interested in the phone system, be it mobile, BT or whatever. I'd like to have a pen pal to write to me purely about any phone system. If anyone is interested in writing to me purely about this, please contact me, and I should mention that Asperger's causes my interests to be extremely limited so I'd need my pen pal to write to me about all the phone systems and nothing else.

Thirteen pen-pal adverts have been held over for publication in the next three issues, Editor.

Pen pal number 185

My name is Jessie, I am 18 years old and I have ASD. I was diagnosed at 11 and I also have OCD which I got last year. It is still here but not as bad now.

I live in Weston-super-Mare with my mum, dad and my two dogs, Archie and Jasper.

My interests are listening to music, reading, TV, films, anime, writing stories and poems, drawing, going on the Internet and walking the dogs.

I would really like to make friends. I don't mind if you are a girl or boy, it would just be nice to be pen pals with someone.

I look forward to hearing from you ^ _ ^

From **Jessie**

Pen pal number 186

Hello, my name is Tom. I'm 19 years old, I got diagnosed with AS when I was 10. I am studying hairdressing, but I get lonely and would like someone to talk to. Also, I think I'm gay, and would like to find some gay Aspie friends my own age. I enjoy drawing, painting, singing, playing the piano and hanging out with people I can trust but I have been hurt by people I thought I could trust.

I also like TV, such as *Peep show*, *The big bang theory*, *The inbetweeners*, *The IT crowd*, *New girl* and *Sherlock*. I like watching movies too, such as *Ghost*, *Casino royale*, *Harry Potter* and the *Lord of the rings* trilogy.

I also have quite a wide musical knowledge and I was brought up with lots of music around me. I am looking for pen pals 18-25 who will write to me maybe once or twice a week, just to help me progress in my mental health.

Troubleshooting relationships on the autism spectrum

A user's guide to resolving
relationship problems

by **Ashley Stanford**

Jessica Kingsley Publishers

ISBN 978 1 84905 951 0

£13.99 / \$19.95

review by **the Goth**

Ashley Stanford has produced what feels like a surprisingly complete guide to dealing with problems that occur in relationships. I have read other books whose aim was to help in this way, but all had failed to tackle the huge, unpredictable, individual range of problems that can occur. By breaking down the advice in a “toolbox” way and trying to teach techniques that can be applied in many situations (just like hammers can be used to achieve many different results, such as nail things, free rusted-in screws, bend things, straighten things) she covers that range without needing to be exhaustive. Examples are given of various uses of each technique to help the reader generalise the tool to use in their own problems, and useful tips and insight into relationships and the autistic mind are plentiful, so the book will be of use to both partners whether or not they are on the autism spectrum. (I’m saying “autism spectrum” here rather than just “spectrum”, following Victoria’s article about labels in *AU* 79 and the letter from Jay in this issue on page 10.)

Communication

I lived
my birth
breathed
air
from my mother
I grew
wisdom

Taught myself
by father’s power
to look after
thee self
by trial error

Formed my knowledge
from everyday life
freedom
as school would not teach

Yet encyclopaedias were given to my hand

by **Sue**

Inevitably, there will be bits missing when trying to tackle such a big subject in a relatively small book, but if you’ve got a spanner and you need a wrench, at least you can recognise what you need, and then ask someone for help in finding it.

And if you find the last paragraph confusing, then thinking about what it means is just the sort of practice you need for trying to understand relationships — and if you’re still stuck, ask someone!

This book and the one on page 18 are available from all good bookshops and through Amazon’s charitable scheme at

www.autism.org.uk/amazon

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

letters to the Editor

Dear Goth,

many thanks for *AU* 77, always welcome down here in Cornwall.

I know it has now passed, but I wondered if anyone else is affected by Christmas. I am 66 and diagnosed with Asperger's syndrome in 2001. I also have depersonalisation disorder, OCD and PTSD, but have always had a problem with Christmas. From the beginning of each December my whole demeanour changes: this year in particular I lost appetite for food and drink and could not eat food that I had previously enjoyed; I became agitated and bad-tempered. Since January I have returned to my normal state. The only thing I can put it down to is that everything changes, there are more people about, buying much more shopping than they need, Christmas decorations everywhere depicting things from a story which is omnipresent, and causing many people stress; for what? "one day".

My other thought is: has the invention of social media sites made it easier or harder for people with communication problems? As one of the problems associated with Asperger's has been face-to-face communication, is social networking now easier for them?

For me, I have not entered into this arena at all, keeping myself safe in the world that I am used to; yes, I may be a Luddite but happy to stay that way.

Lastly, thank you for the *Passport to individual autism support*: such a good idea. I have completed mine and have made several copies: along with the *Autism alert* card, they give a much bigger picture for those who need it. Well done.

Many thanks,

L Haag

My name is Lisa. I live in the US. I have had selective mutism since age 6 or 7. I was not diagnosed or treated as a child, but I remember feeling different from other children at school. I was the only one who wouldn't talk to the students or interact with them. I would talk to the teacher, especially when the students were outside playing, and we were alone in the classroom. Then, I felt comfortable, and would talk to her and act my normal self.

As an adult I still feel that something is not quite right. I am nervous around certain people, and different social situations. I like to be alone more often than with others. I took an empathy test online, and scored 26. The results were that if the score is 30 or below, I have a lack of empathy, common in people with Asperger's.

I hope to make improvements and live my life more freely than I did in the past.

Sincerely,

Lisa

Dear Goth,

I feel I have to respond to some of the points made by Victoria about labels. She says that "autistics" is horrendous because it sees nothing but disability: I reject seeing autism itself as a disability, so I prefer to be an autist, an autist with serious anxiety, sleep and overload problems, none of which I see as part of autism, but brought on by my environment and society.

"On the spectrum" is simply shorthand for "on the autism spectrum", so the many other spectra out there are free to be their own spectra and be invoked when the context requires. And yes, spectra do go on forever: autism blends smoothly into the "general population". There is no obvious dividing line; diagnosticians just have to pick a certain level of autism-type difficulty with life and say that anyone with more difficulty than that is autistic. So yes, everybody is on the autism spectrum, but most are on the other side of the fuzzy dividing line between "blue" and "green".

Yours sincerely,

Jay

Dear Editor,

I suffer overload I call a “deep autistic mode” (DAM). It is tied up in suffering as an Asperg, in covering up you are different, and how. It is part of our being. We do not know how our brains work: we consciously think but most is done automatically — this is the same for an Asperg. We have limited control of the Asperg part of our brain. I can sense an Asperg happening coming on till it gets so obvious I have to accept it will happen; I can humour it to lessen the effect if caught in time, but some situations happen so quickly, especially the last fourteen years and four months. I can describe how it affects me, but not the way it goes about it.

I did not have DAM incidents in my childhood. I was different but not extreme; the occasional DAM started in my late teens, their frequency gradually building up as I grew older. The deepest bout was four days and nights taking to my bed, going whole days before relieving myself, feeding and so on in the dead of night. Afterwards I thought I felt as ordinaries felt; immediately the Asperg influence would start to affect me again, gradually building up. It could be months, a year till the next one, in my younger days. The days after a bout I was euphoric, glad to be alive and free of weight on shoulder. I learned I could change lifelong routines during this euphoria, with no problem: I changed a lot of bad habits that seemed to be a part of me before.

The majority of me being Asperg is allergy to meeting people. In my extravert Asperg me I could deal with anything, or appear to be, as long as I felt in control. As Asperg stresses became stronger I had to watch what I undertook in public, and just before a DAM I had to be wary among people, as my brain seemed to be frozen in dealing with conversations. So I could say hi and small talk, but got very upset if things got complicated — then I could appear cold-hearted.

Up to my late forties I was able to lead my life around my Asperg, sure people were puzzled by my odd behaviour, but that was just me. Nobody ever saw me in DAM, only my immediate family

knew what went on. I always saw it as part of life, not that I was disabled or ill, something that had to be borne as best as possible. I would always pick myself up after problems with people: it was always people upsetting me, even if I did not realise at the time, that led to a DAM incident, and I rushed into something new if it was caused by someone doing something really bad to me.

As life gets more stressful as I get older things started to stack up, more problems together. I was diagnosed at 49: I thought this was a new horizon. How wrong can you get? I was told it would lead to disillusionment when nothing changed; I was still the outsider trying to get near the centre of humanity. Two years later I was still being abused by managers at Social Services and doctors, who willingly covered up for the managers. I now find myself in almost steady DAM or just below it, ready to suffer from it at the slightest provocation, denied my rights to justice and medical care. The Social Services, shrinks and GPs are now the triggers for the worst DAM can throw at me, and sleep has returned as it was as a child: restless, fitful, kicking, which is how I reckon I dealt with my Asperg as a child.

It must be easier for me to describe what a DAM does to my brain if only ordinaries could see more than a guy who acts mostly as if nothing is wrong with him while my brain is crying out for relief from stress. Since I drove Social Services out of my life in '07 I have gradually returned to normal, able to communicate, except with my abusers, as long as Social Services do not intervene, though they have kept tabs on me for the three years since they invoked mental health legislation. I have not had any benefits from that, but plenty of drawbacks, as people now treat me as mentally ill.

A key measure of the level of justice and compassion in any society is how it treats its vulnerable!

Yours sincerely,

Eric

Banshee diary

by John

I called to them again today. They just ran away. That is, apart from the one who I was calling for. To be honest I was glad that they ran, even though it still hurt a little. Not because I like knowing that people fear me. It still feels horrible knowing that, it's just that I'm aware of what the alternative is. Even as a child, I knew that they'd want to kill us, although I still didn't really get it. What child would?

"But if they understood us," I'd said to her, "it wouldn't have to be like this."

My mother just smiled at me, like she knew that I'd eventually see it her way, so she didn't even see the need to argue with me. But I could see a sadness too, and not just for herself. When we get used to them, we're able to accept so many little injustices with barely any complaints. But it's so much harder to endure it when we know that our children will have to suffer them as well. I guess that's why I never became a parent, it just seemed too cruel, to bring something beautiful into the world when people would only hate it.

"No, my child. I only wish that were true. The humans don't want to understand, all they want to do is fear, and then kill the thing that caused them to fear. Why would they need anything else?" She gave a bitter laugh, then she must have seen my reaction, because she just hugged me tightly to her, and tried hide her sobbing.

At this point, what you should probably know about me is that I'm a banshee. As in, I wail at night, usually somewhere near the coast, and someone dies. The humans don't really agree if I cause someone to die, or just foretell the death. But honestly, if I could choose not to call to them, and that meant that the person would live, believe me when I say I'd not be doing this. But mum told me that if I don't call that person, I

die in their place. And although I've considered it, and sometimes even delayed my call a little, it hurts. It hurts a lot.

Each time I tried to hold on for longer, hoping the pain would end and no one would die. But as far as I could tell, it never did end, and only really got worse. So I satisfied myself that it really was them or me. Does that sound better, or worse? It's been such a part of me for so long that I don't even know anymore. But it's important that you know why I chose to keep calling for them, and that it wasn't a choice that I took lightly. Every few years I re-consider if it's really worth knowing what I'm responsible for by keeping going, but I've not changed my mind so far. I suppose if you humans stopped fighting your wars, or murdering each other for profit, it might be harder for me to justify.

How to describe what it's like when I call someone? It's basically just an urge, at first. I just have this feeling that I need to go to this place, and in a few days I have to call someone (I don't really have any idea who they are or know anything about them, I just know where they are right now), and when I'm done calling, they're dead. When it feels like I need to call, then delaying it any longer brings on the pain. When I'm done, I don't get a rush or anything like that, I'm just glad that it's over for another month. And I'm fully aware that someone had to die, and what that means.

I said they were afraid of me, and it seemed like they were, but now I'm not so sure exactly, and I've got the awful feeling they might be coming back. It's just something about the noises, or more exactly an almost complete absence of the noises I'd expect to hear if they were just waiting it out further inland. I should have mentioned that when I call for someone, I actually have to see their body for the whole me-

a fable (continued), and a letter

not-dying thing to work. That's a little tricky for me, because ideally I'd be in the water. I'm not aquatic, but I'm vulnerable here. This could be bad.

That's how they got mum. I hope they don't get me like that, but I'm only getting older and slower. It's really only a matter of time, and it is the natural order of things, except for the part where I'm a banshee. All I can do is hope that it won't be today.

She could have lived. She could have fought them. I was much younger then, and slower than her. It somehow makes it worse that her last act was to rush the ones who had hold of me, letting me go. At least I didn't have to see it. For a long time I felt responsible, but I'm wiser now. The men were stupid and ignorant, and they didn't even care. If she hadn't have saved me, they'd have killed me instead, and would I have felt responsible then?

Oh no. I can see torches. They're going to burn me. Well, I've no real reason to stay here any longer. I got what I came here for, and now it's time to leave. I run, like I did all those years ago, although this time I'm much faster and they don't have a hope of catching me. I'm in the water before they'd even be able to see me. I say a few words of thanks for my mother, although she's not there to hear it because of people exactly like these idiots today. I honour her memory by surviving her, and I fully intend to keep that honour for a while yet.

Maybe some day the humans will learn, will see what I really am and what I'm not. The optimist in me hopes that this piece might go some way to making that happen. I know I can't allow too much optimism. But maybe, for the first time since I was a child, I'd be able to live without fear, without having to hide what I am. I hope I'm alive when that happens, but for now I just keep running. All I can do is to always remember those who I was forced to leave behind. And never look back.

Hello reader,

I did not attend my mother's funeral. Reader, what are you thinking? Hated her? Loved her? Indifferent to her?

My mother is the only human to which I bonded. Her death did not eviscerate that bond. Reader, I am guessing that you are now thinking "loved her". Or perhaps, if you are a logician, "loves her".

I was not diagnosed with AS until after the death of my mother. She did not know that I was autistic. She did know that I was different, very different. I lived with my mother as child and adult until her death. I have never bonded with other family members or humans in general. I have never had a girlfriend. I have never had a friend. If I was in work then I would always come home straight from work. I never socialise. I never go to the pub or to the theatre or anything similar. I never go on holiday. I do not drive. I do not read books (sorry Goth). I have no interest in gadgets. Reader, do you think this is a recipe for a happy life? Reader, is your conclusion "no"? I think the conclusion "no" is likely.

Reader, from what I have read in previous editions of *AU*, I think your conclusion (if that is your conclusion) is correct. But not universally correct. I am happy (sorry Edward) with my life. My mother did not understand my happy outlook. How could she? She did not understand why her son was not open to that which gives humans pleasure? But she witnessed and accepted that her son was not open to these things and she witnessed and accepted and was glad of the fact that he was nevertheless happy. My mother knew that the menu of things that made her son happy was stunningly brief but thankfully sufficient.

Reader, one of the many reasons that I did not attend my mother's funeral was my perception that people would say "sorry for your loss." My mother's death was for me not a loss but a lessening. My bond with my mother remains. It is and will always be so (is that a line from *Star Trek*?).

Writer

a letter (including a poem) and a notice

Dear Goth,

Thank you for the work you do editing *AU*. I always find something that resonates and often want to write, to tell others that it is possible to have relationships and children, and to be a good parent. My three adult children are bright and capable in the world, although at least two are also AS. It runs in families — one of my brothers, my father and one of his brothers — and I do wonder about a genetic link with ADHD as I've seen that in several affected families, including my own.

I only realised that my life-long difficulties with the human world were due to AS at the age of 50, through meeting a now dear friend who also struggled with this and had her daughter diagnosed. It made sense of everything at last. I'm one of those who reacted with great relief, and tried to find out everything I could. I also suffer with prosopagnosia, as did my dad, and my son, and I find it very hard to remember names, too. I generally don't recognize people in a new context or after a passage of time. Now I simply tell them on first meeting that I'm sorry, I will forget their name, and please remind me next time we meet. It helps to be upfront about it and most people respond with a laugh, and "Yes, me too."

The reason I'm finally writing is Neil's article *Aspie* — *and proud* in Edition 79, where he identifies subgroups. I would say they are all behaviours and have displayed all three of them myself at different times, but it really helped to see "passive" listed, as that is the one I struggle with the most. This morning I wrote the following:

This – hesitancy, this – paralysis, this – whisper its name –

fear

and its other name

grief

keep naming it

anxiety

Outside, sparrows squabble and chirp.

Sunshine fills the kitchen where I sit

listening to the hum and rumble of the old fridge.

Keep digging. This goes way back.

This is the lost child.

Woodpigeon coos at me,

water's running next door.

I write lists. What needs to be done.

Rooks caw. I sit with the child inside me,

the one who learned not to speak.

I cry her tears. Feed her toast and jam.

Put numbers into squares.

Tell her she is wonderful. Clever. Brave.

She still doesn't believe me.

Best wishes,

Jo xx

If sufficient material is sent in, the theme for January will be **creativity**. Vote with your contributions: the more submissions on a subject sent in (from different people), the

more likely that that subject will be the theme. Writing on any subject is still welcome, as is artwork. If you want to see different content in *AU*, the way to change it is to send something in!

Dear Editor,

thank you for printing my piece on the Asperger snob. I expected a mixed response and it showed a measure of moral courage and editorial integrity that you included the article in January's *AU*.

I hope the generality of readers will have realised my aim was not to offend, but rather, to alert people with Asperger's to the creeping indifference and cynicism of a public, weary and wary of -isms and syndromes. By way of example, I overheard the following exchange at my place of work, just two weeks ago:

A: "None of them control their kids."

B: "Yeah, then they say they've got ADHD or Asperger's disease." [sic]

Moving on . . .

It has occurred to me that a theme worthy of discussion in *AU* might be: the difference a diagnosis of Asperger's can make to one's employment prospects.

I am very fortunate always to have been in work. But, only my current employer — of five years — has knowledge of my condition. Previously, I hadn't been diagnosed and so I too was somewhat in the dark.

Employment involves conforming, co-operating and communicating to an accepted level. All of these skills I have found difficult to acquire or to sustain in the workplace. Hence, keeping jobs for long periods has been a problem for me. On paper and at interview I can present an image of employability. Post-interview, by degrees, the "real me" emerges, causing unease among colleagues and conflict with my managers.

I am, consequently, familiar with the various rituals of dismissal, although often enough I've jumped before being pushed. Nevertheless, with a little creativity in the CV department, I continue to find work.

My current situation is very different, because my employer knows about my diagnosis and its presentation in my behaviour. So, although many of the usual difficulties arise, compromises can be reached and it is understood that I don't intend making waves.

At fifty-eight years old, retirement is in sight and my own struggle with the world of work nears its end. However, many others will be still in the thick of it or even between school or college and their first jobs.

I am acquainted with two other people with diagnoses of Asperger's, for both of whom employment is their single biggest concern. One is middle-aged and thus far been either unemployed or in part-time, low-paid work. The other, in his late twenties, has never been in paid employment.

I wonder, what proportion of the Asperger's population is in a similar position, that is, underemployed, and what difference the diagnosis might make in triggering the intervention of support services. It seems inevitable, given the nature of the condition, that without help many people with Asperger's will exist on the margins of society, suffering the "slings and arrows" which come with their socio-economic status.

Do any readers have experience of support services in this regard? Is this an area in which the National Autistic Society is already involved?

I look forward to reading responses to these questions from readers of *AU*.

Yours faithfully,

Edward

PS. I read with interest Julie's article in *AU* 74 and 75, which eloquently described difficulties for those *in* work. However, getting *into* work in the first place presents a different set of problems.

Dear Asperger United,

I wondered whether you would list my autism website (including links to my forum and Facebook page) in the magazine:

planetautismblog.wordpress.com

“Aspie burnout” is a colloquial term that the clinical world doesn’t seem to acknowledge as a genuine part of the autistic spectrum, resulting from the attempts to “be normal”, fit in and keep up. It can creep up on you, it can hit any time, but for sure, most Aspies will have experienced Aspie burnout by the time they hit 35.

Basically, the higher-functioning you are, the more others expect of you and also, the more you push yourself. You have an invisible disability, you look normal and have no apparent physical difference. So why can’t you behave and carry on like everyone else? Sure, everyone gets tired; sure, they also can get burnout from pushing themselves too hard. But the difference is this: we get it from just existing in a neurotypical world, a world that doesn’t accept our differences or make allowances for them. Mental health issues are greater in high-functioning autistics, because of trying to fit in and finding it so difficult. Because we are acutely aware of our differences and our failings, but we are just as affected by them as lower-functioning autistics. So we kind of have the rawest deal.

People say to you things like, “Other people manage why can’t you?”, which only serves to make you more insecure. There are low points, when you are angry at having autism and being different and having no control over it. Those moments are exacerbated by such unhelpful remarks. When you have brain differences, when you literally get overwhelmed by so many environmental things, just existing is challenging. So when you try to take on responsibilities that other people find par for the course and take for granted, they can become massive challenges to someone like me. And ignoring the difficulties, carrying on as you see everyone else doing, at some point, will ensure a mental and physical

collapse. This means, you can’t go out, can’t even contemplate doing the most basic things without great difficulty. The saying “something’s gotta give” comes to mind. We need to pace ourselves; there is only so much we can manage. Trying to do it all can only work for a limited time.

If you Google “Aspie burnout” all that comes up is a collection of blogs and websites. The very real experiences of us Aspies. But there is no clinical term for this specific condition, no doctor seems to be aware of it. When you hit burnout, you can take a long time to recover. Even one stressful day, for someone on the spectrum can mean days or even longer, of hiding away to recover afterwards. So imagine what impact it has if you try day after day to continue living at a level which to others is ordinary but to you is a massive challenge. And once you burn out, your coping capacity is diminished. That means, even when you recover, if it happens again, it can happen quicker and take less to provoke it.

I have read of one author who has written about Aspie burnout: Suzanne C Lawton refers to Aspie burnout as “the Asperger middle-age burnout” in her book, *Asperger syndrome: natural steps toward a better life*. On page 33 it says:

“She had noted this same behavior and attributed it to adrenal exhaustion from years of pumping out high levels of epinephrine from prolonged severe anxiety. Not only were these AS people dealing with their regular levels of anxiety, but they were also working extremely hard to maintain a façade of normalcy.”

Although, I don’t think that it only applies to middle-aged Aspies, as I have read of younger Aspies having it too. I think it depends on your unique balance of traits, the support you have and your environment as to when you get it. Some may be lucky to escape it, but I think that is rare. So us Aspies must remember, to stop pushing ourselves too hard, think of what we need, and be kind to ourselves. Don’t be scared to say “no”.

Planet Autism

The First Thursday Book Group

by **Caroline Henthorne**

A warm summer evening in June saw autistic adults in South London not heading for Clapham Common after work to enjoy the sunshine but making a beeline for the nearby Clapham Library. Fulfilling the autistic nerd stereotype? Far from it. We were going to a fun new group, it was the first meeting of the First Thursday Book Group.

The First Thursday Book Group is a relaxed social environment for autistic adults (no formal diagnosis necessary). We share our views on the month's book over a glass of wine and all opinions are welcome whether group member have read the book or not.

That June evening we discussed the political thriller *The ghost* by Robert Harris which provoked a lively discussion on Blair's government. Since then we've read, psychological dramas, and a comic novel. The group members pick what we read.

The book group is low-cost: books are supplied by Lambeth Libraries (you don't need to live in Lambeth to join the group) and group members just need to pay for refreshments.

We meet at Clapham Library (Mary Seacole Centre, 91 Clapham High Street, SW4 7DB) where we are lucky enough to have a quiet room with natural light. We're there on the first Thursday of the month from 6.30 pm – 8.00 pm.

The Lambeth branch of the NAS started the book group in partnership with Lambeth Libraries. I am a member of both organizations and host the group. To join the group, email the Lambeth branch of the NAS at lambeth@nas.org.uk, or call into any Lambeth Library and ask at the welcome desk for the First Thursday Book Group, facilitated by librarian Andrew O'Brien.

Calderdale

Upper Valleys Autistic Adult Group

A social, support and action group, run by and for autistic adults.

Based in Hebden Bridge, the group is open to any autistic adult able to get to meetings.

Unless on the autism spectrum themselves, this group is not for parents, carers and "professionals".

Autistic space, to be used by autistic people for autistic needs and autistic empowerment!

Please contact **Ruth** for further information:

07742 534 590

k.genyin@googlemail.com

AutismCon

notice by **Daniel Jeffrey**

A new and very exciting event will take place for the first time — AutismCon — which is planned and put together by and for people on the autism spectrum. The day will include more than just talks — we'll have performances, workshops and games about autism and lots of other topics, too. But it doesn't end there: in the evening there will be a dance and social event, with special guests and fun to be had. AutismCon will be held at Conway Hall, London, on 17 January 2015.

To book your place, contact (preferably by email):

Elly Badcock
NAS
393 City Road
London
EC1V 1NG

Eleanor.Badcock@nas.org.uk

020 7923 5716

The independent woman's handbook for super-safe living on the autistic spectrum

by **Robyn Steward**

Jessica Kingsley Publishers

ISBN 978 1 84905 399 0

£13.99 / \$19.95

review by **Laura**

Robyn Steward is only 26 years old, but has a lot of wise advice to offer in her book, offering many safety tips for women on the autistic spectrum.

The most important thing she notes is that it is not possible to guarantee absolute safety; however you can learn to understand and reduce risk. She covers important issues of daily life including friendship, sex, alcohol, the Internet, money, and mental health, providing information to help you make informed decisions about your actions.

Robyn uses a variety of pictures, diagrams, charts and lists to help explain things clearly, whatever your best learning style. She summarises each chapter to help you remember the most important points. This book is filled with many useful tips that are useful to look back on again and again.

My only criticism is that I feel some of the advice is too simplistic to apply to all situations. For example, the book advises never to lend money to a friend. I feel that there may be situations where it would be appropriate to lend money to a friend, and that it's not necessarily right to make a blanket policy on everything. However, it would be impossible to explain all the nuances of life in one book, and I feel the advice offered makes a good starting point for anyone

wanting to learn how to keep themselves safe. As we are all very different, you need to make up your own mind based on your own needs and experiences.

This is an excellent book for any woman on the autistic spectrum, and for anyone who loves or supports a woman with autism. The advice may well be useful for many autistic men as well, but it deals with many of the unique issues faced by women and offers very sound advice on how to keep yourself safe.



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 be for 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) *Asperger United* is free and is quarterly, published in January, April, July and October. If you do not receive a copy when you expect to, please contact AU.
- 3) Pieces that appear in *Asperger United* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 4) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- 5) *Asperger United* 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. Please consider getting involved with the NAS campaigns and events.
- 6) If you move house, please inform *Asperger United* and include your old address as well as your new address.
- 7) 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.
- 8) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as 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 your record.
- 9) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 10) The current edition of *Asperger United* is available at **www.autism.org.uk/aspergerunited** You need to scroll down to the middle of the page, where there is a link to the PDF.
- 11) You can sign up for an email notifying you whenever a new edition of *Asperger United* is posted on the webpage above. Email **asp.utd@nas.org.uk** asking for the notification by email and please include your full name, postcode and let us know whether you want the paper edition too.
- 12) If you want to unsubscribe from the paper version, inform *Asperger United* and include your postal address. Or to unsubscribe from the email notification, include your email address.
- 13) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address (for the paper version) or email address (for the email notification).
- 14) 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.
- 15) 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.

Volunteering opportunity at *Asperger United*

Publishing and Communications Assistant

notice by the Goth

Asperger United is looking for a volunteer
Publishing and Communications Assistant.

The successful candidate will learn about all
aspects of *AU*, including:

- subscribing people
- copyediting
- laying out the magazine
- proofreading
- printing and distribution of the magazine.

There is also the opportunity to learn
about other roles in the NAS's Publishing and
Communications, and Digital Media teams.

4 hours per week, expenses will be covered.

The ideal candidate should:

- live in the London area
- be computer literate
- have a high standard of English
- have a clear writing style, and
- be committed to the ethos of *Asperger United*.

A full job description and application form
are available on request from

asp.utd@nas.org.uk

and also on line at

www.autism.org.uk/AUrecruitment

Please note that information is available only
electronically, due to the need for electronic
communication in the role.

Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG
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Website: **www.autism.org.uk/aspergerunited**

