

Produced by and for autistic people

# Asperger *United*

Edition 90 April 2017



# Asperger United

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*Asperger United* is a magazine run by and for autistic adults (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.

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**Please send all correspondence and subscription requests to:**

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

*Asperger United*  
c/o The National Autistic Society  
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Tel: **0808 800 1050** (free from most landlines) or  
Tel: **020 7923 5779** (geographical charges apply)

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.

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*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 email address or postal address above.

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Contributions for the next issue should reach *AU* by **8 May 2017**

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

I hear that my whimsical editorial last issue caused some of you some confusion. At heart, I was being silly and there was no more sense in what I was saying than in the poem *Jabberwocky*. Some of you also tried looking up the names I used in a dictionary, but of course, dictionaries seldom include names — googling them would have been more effective. I hope you aren't too annoyed with my sense of humour.

I'd also like to remind people that you can send submissions on any subject. If it doesn't fit the theme, I might publish it anyway. Not everything in the magazine fits the theme — it's only a guideline to help you write something, if that is the sort of help you need. Please don't feel you can't send something in just because of the theme.

On the back page of the magazine is an advert for Autscope, which I again hope to attend, and to see many of you, both new and old, especially as it is in a very central location compared to where most readers live — Northampton. More readers live within two hours' travel than for any other Autscope in the past six years.

On the downside, I can't imagine that Northampton offers the beautiful countryside of recent years, but seeing more of you will certainly make up for that!

yours,

**the Editor**

PS. In these days of computers, postscripts are unnecessary, as you can just edit the text!

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## the anxious edition — suggestion for next issue on page 15

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**Dear AU,**

I wish to contribute to the magazine on anxiety.

I received a diagnosis of Asperger's syndrome at the age of 53. I have had another breakdown and am back on medication for the third time in seven years. This latest breakdown was caused by the build-up of pressures at home resulting in an overload of anxiety.

I recognise that most of my anxieties are probably due to being Aspy. I am not a quitter. I am a finisher. I am a decision-maker. I tend to pursue a goal beyond the limits where others might just give up. The bigger the challenge the better and sometimes that is not good for me or my family because I don't know when to stop.

My anxieties are normally caused by the way I respond to external influences on my life. This could be a rise in council tax or water rates or a cut in benefits. It could be the introduction of new traffic lights where none has ever been needed. It could be the way other people treat me at work, in the street and at home. It could be conflict in a relationship whereby the partner has expectations of me. I feel that others are trying to take over my life without my consent and that causes me stress and anxiety. I like to be asked. Add to that hypersensitivity with noise and touch and my mind is a time-bomb of anxiety. I have to control my environment as much as I can.

My main disability is in the area of theory of mind. I cannot predict how another person might behave or what they might be thinking. I misread body language. Although I can predict a person's needs at a practical level I cannot do that in a relationship at an emotional level. When a partner has expectations of me I really do my best to try and meet them. However, I usually fail when it comes to emotional expectations. I can't think on that level on the hoof. I get as much out of being with a cat or a parrot as I do with being with a human. But animals are easier to be with because with them there are no emotional expectations. I think even some NTs might sympathise with that one.

As an Aspy in a relationship I don't know when to let things go because I can't see the effect it's having on the NT until I end up anxious and depressed. It works like this: I think my partner has expectations. I try to meet them but fail. They get upset and I think it's my fault. I make it worse by trying to sort it out and they get frustrated and explode at me. The shutters come down, I withdraw. Partner apologises. Twenty-four hours later the shutters come up and I relive in full Technicolor the video of the incident which I play over and over again causing me great stress and anxiety. It takes about four days before I can turn off the video and return to normal by which time there is another bag of expectations to deal with. I like having a partner to share life with, but a woman's needs can be manifold.

My initial response to shutdown inside is something I think I developed in childhood. My mum was quite violent towards us children. My teachers used to slap and punch me. Fellow pupils would make fun of me and I was severely bullied during my three years at an army apprentices' college. By the time I was 18 I was used to being a punch bag for other people, emotionally and physically. My response then, as it is now, was to shut down and hide away. What might then happen causes me great anxiety.

Coping with anxiety has led me towards harmful behaviour, abuse of alcohol being the major one. In dark times this has led to self-harm and attempted suicide. Nowadays I have learned other strategies like controlling my environment and activities to reduce anxiety to an acceptable level — that is, zero! A course of cognitive behaviour therapy has been very useful.

Family life has become very difficult. I love my daughter. I love my wife. But having them together in the same room has become more and more difficult for me ever since my daughter became a voice, presence and challenge for her mum. She is 11. In the present crisis I live at a friend's and visit the family home daily. Everything is amicable and it's working for us. I'm doing better and my wife is too, not having an anxiety-ridden husband to contend with.

I've noticed with age my tolerance levels for coping with anxiety are reducing. I'm kind of accepting that if I'm to remain living in society I'll probably have to be on medication to control anxiety for the rest of my life. But that's no different to other lifelong conditions like diabetes, is it?

For now I've limited my responsibilities. I live simply and avoid stressful situations doing only the essentials. I stick to the acronym HALT: don't get too hungry, angry, lonely or tired, and I stay occupied in enjoyable distractions.

Christopher

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## Coping with anxiety

by Chris

I only found out about Asperger's in the past eighteen months and was diagnosed when I was 41. I've wanted to write something for *Asperger United* ever since I subscribed.

When I found the theme for the next magazine was about anxiety I thought there must be something I can write about. But what? Thinking about it and worrying about it was making me anxious. So, I did what I normally do if something is making me anxious. Stop and think. Eventually thoughts and ideas form and I write them down. Once they are on paper the anxiety starts to go away.

What do I need to reduce my anxiety level? What do we all probably need? Time and space. To be alone and to think and collect our thoughts. I've always retreated to my room at the end of a busy day at school or work. My parents have let me do this. I've never been pushed to socialise or make friends. It is not what I wanted to do. I am much happier reading a book, watching TV,

working on my computer. It has been like this for thirty years. I've been very dependent on my parents, but am able to live a fair proportion of my life independently.

All my adult life I've tried to do the things I want to do, buy the things I want to buy. I've never let peer pressure bother me and I think that is very important. A lot of the people I've found myself surrounded by at college and work have been older than me or younger than me. I've never tried to make friends outside of college and work. If people want to talk to me that is fine, but I won't go out of my way to try and be sociable and I certainly avoid small talk like the proverbial plague. My anxiety is always caused by other people. On my own I am fine and quite content.

Having a hobby reduces anxiety. I must have a dozen hobbies. I can chop and change between them all as the mood suits me and if I get bored of one I do something else for a while.

Going out *does not* equate to socialising. I can go out, but I don't have to talk to people. I don't go to pubs and or cinemas, shopping, or any of those sorts of places. Places I go are quiet — the seaside or occasionally I go to a book fair. I don't go out very often, and it is usually on a nice day so I can take some photos. My recent holidays have been on my own and I stayed clear of all the town centres but still managed to have full days out.

Everyone has anxiety at some point. By getting out and doing things you learn to cope with that anxiety and find strategies that are good and bad for dealing with it. The good things you do again, the bad things you don't.

Now I have to pluck up the courage to hit send. There. It's gone. Sent. I cannot change what I've written. Are there any mistakes in it? Will it be published? How long is it until the next edition? *Arrggghh*. I am starting to get anxious. But is it anxiousness, or it's close relation — anticipation?

## three letters and a notice

Hi,

I would like to know if anybody can give any useful advice on coping with groups of people.

Are there any self-help books available?

Sometimes I go through rough times where I feel I can't deal with things or where I feel I cannot communicate with people and that I should just go into shutdown mode. What does this mean?

Thanks again, Goth. Hope to hear back soon.

**Barry**

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**Hello *AU* bookworms,**

I am an individual with autism. I am different. It is very clear that many do not like any to be different.

I happened to come across this quote, "Be yourself, everyone else is already taken." It is a quote from Oscar Wilde. This makes sense to me as I take the view that trying to be anyone but yourself will eventually eviscerate your mental health. And then I came across this quote from Ralph Waldo Emerson, "To be yourself in a world that is constantly trying to make you something else is the greatest accomplishment." So, to be yourself is not only good for your mental health, it is recognized as being the world's best accomplishment. Who knew?

I may be giving the impression that I am something of a bookworm — I am not. Indeed, whatever the opposite of bookworm is, I am. I do not like books — d'oh. I like TV, including, as you may have guessed, *The Simpsons* — d'oh.

**TVworm**

PS. I like *AU* as well — D'oh!

## Resubscription project

### notice by the Goth

More of you have received a flier with this magazine asking you to resubscribe. Please respond in one of the ways listed on the flier. People who don't respond will be sent fliers three times, and after that their subscription will end.

But please don't worry: if you want to continue to receive *AU*, just respond!

If you have not received a flier there is no need to respond, though if it puts your mind at rest, please feel free to let me know you want your subscription to continue.

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**Dear Goth,**

this is the third email which I have sent you within less than a week, and I promise it will be my last . . .

I am full of admiration for your editorial skills — each issue of *AU* reveals the amount of care which you take over every issue, and your "mission" to provide a high-quality, responsive, and relevant product for your subscribers.

I noticed your suggested theme of mental health, but, in a way, that seems a little sad — it suggests that Asperger's syndrome is some kind of deficiency.

But, ever-so-slightly-tongue-in-cheek, might I suggest that Asperger's could also be viewed as a "lifestyle"?

Can I suggest, for a future issue, a theme called something like "my perfect holiday"?

Best wishes,

**Kevin**

# Pen pals

## Pen pal number 237

**My name is Craig,** I am 33 years old and live in a flat on my own in Somerset. I have got Asperger's syndrome and dyspraxia and am also gay. I was diagnosed with Asperger's syndrome and dyspraxia in 1996 when I was 13 years old. My hobbies and interests are walking my border collie dog, going to the cinema, watching film and tv series, dvds, going to the gym, listening to music and meeting up socially with friends and family. I would like to hear from anyone around my age or older.

## Pen pal number 238

**Hi, my name is Steve.** I am a 48-year-old gay man.

Most of my life has been spent as the outsider of the group. I struggle to make friends as I never know what to say.

Recently, I had a pre-diagnosis done and am now still waiting for the official diagnosis.

I love going on my laptop, watching DVDs, sci-fi, cooking shows, dogs and budgies. My music taste is very eclectic: Sixties, Eighties, Elvis, Motown, Two-Tone, plus many new artists.

I would love to make friends with anyone around Shropshire or the Midlands. I prefer people to ask me questions as my conversation imagination is poor.

Thanks for reading this and hope to hear from someone soon.

## 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*.
- If you get no replies, please don't take this personally.

## 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](mailto: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.

*Sixteen pen-pal adverts have been held over for publication in the next four issues, Editor.*

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### Pen pal number 239

**Hi, I'm Sean.** I am 23.  
I have ASD and OCD.

I enjoy reading and writing. I can speak basic Spanish, as I lived in Spain for a year, and a tiny bit of Japanese, but I would like to learn more.

I really enjoy cooking and art. I can be shy but like to make friends. I am very interested in history and mythology. I have studied it a lot. I enjoy all kinds of music and films usually, if I think it looks good or sounds good.

I look forward to hearing from you.

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### Pen pal number 240

**Hi, my name is Luke,**  
I am 17 years old and I live in Liverpool. I have Asperger's syndrome which makes it difficult for me to make friends. I like playing the guitar, listening to music, football, *Star wars*, Marvel, and watching movies.

I would like to hear from others who have similar interests and who are around the same age (16-25).

### Pen pal number 241

**Hi! I'm Edward.** I'm 17, and I live in Ireland. I have Asperger's and I have been diagnosed since early childhood (it's mild though). I have an interest in video games, reading, anime, physics, movies and chess. I'm looking to write to a person my age because most people I know who have AS or other learning difficulties are around ten years older than me. Also I attend a mainstream school (no SNAs needed). Any intellectual or fun discussion is welcome.

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### Pen pal number 242

**I am a 60-year-old female,**  
diagnosed only three years ago. I also have dyspraxia, diagnosed about two years ago — both privately. I would like to befriend others who have been late-diagnosed. I love animals — I have cats and chickens and hopefully this year a retriever pup. I love reading and studying; I have done numerous jobs over the years; went to university aged 47 to become a nurse; and now for the second time am a registered childminder. I love driving and walking and the seaside and would love to have great in-depth conversations about anything, really, and to find out how others cope with this diagnosis so late in life.

Thank you,

Sylvia

### Pen pal number 243

**Hello, I'm Patricia,** 42, was later-in-life diagnosed with Asperger's. I love animals, wildlife, cinema, reading and colouring. I'm from North-East Scotland. Would like to write to anyone 25-plus.

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### Pen pal number 244

**Hey everyone, my name is Jackson.** I'm 32 and I live in the London area. I have Asperger's since I was 13 months old.

I like going to the cinema, watch TV, online, YouTube, play video games (old and new), hanging out and travel, listen to music, arts and craft, theme parks and karate.

I attend comic conventions near and far as I'm interested in the media both from the East and West. I am a fan of Marvel and DC (films and comics) and anime and manga. I enjoy them so much that one of my main hobbies is making and crafting outfits and props from those series and franchises. Plus I even started writing a novel (first in a trilogy).

I hope that I get the chance to have a pen pal that has the same kind of interests or have someone to write letters to so that we can get to know each other better.

Jackson



## My Dear Goth,

in common with many Aspies, my polite and precise manner of speech belies my Scottish working class origins. It is also widely recognised that Asperger males can sometimes be perceived as effeminate by their peers. Both these factors have exposed me to a lifetime of prejudice through inverted snobbery and homophobia, both of which are endemic in this grim sink town, where I remain trapped by poverty and lack of appropriate support.

Five days ago I was terrorized by four people on a local footpath I've walked since I was a child. It began as a homophobic hate crime, compounded by wild allegations of being an offender, triggered entirely by my accent, when one of these strangers asked me for tobacco. The raw hatred displayed by these thugs placed me in genuine fear for my life. My existing anxiety disorder has naturally gone into overdrive since. Sometimes I start shaking and burst into tears without warning and every muscle still aches from my panic stricken flight from that familiar place.

These perceptions and prejudices must affect other Aspie men, regardless of their sexuality. It is important therefore to make people aware that the police treat all homophobic verbal or physical abuse as the same gravity of hate crime, whether the victim

is gay or not. Indeed, the lovely WPC who took my statement never even *asked* about my sexuality, it just isn't an issue and doesn't alter the nature of the crime. Just for the record, I haven't had a date in over fifteen years, so the gender of people I don't sleep with is a somewhat abstract concept! In the right circumstances I might fall in love with a person :)

Police officers are intelligent people who dislike bullies as much as we do. Individual officers may not be autism-trained, but they are sympathetic and will readily offer liaison with a colleague trained to speak to vulnerable people. Even if someone shouts "poof" at you in the street, or harasses you in a bar, they want to know about it, and will treat the offence on a par with racial abuse. Verbal and physical assault are deemed equally serious. At the risk of repetition, it does not matter whether you are gay or not.

Although I was lucky not to have been injured, the police have advised they will be seeking convictions, with a real likelihood of custody as the outcome. It is also urban mythology that the police cannot act without witnesses: CCTV is everywhere and can place people near the scene and time of reported crimes; this and a victim statement is enough to press charges.

Since reporting the incident, I've been contacted by the police, Victim Support, my

local councillor, and have even been invited to an interview with my MSP — all within five days. Every one of these agencies has been shocked to learn I've received *no* autism support from any quarter except my GP since receiving my autism diagnosis three years ago, even during cancer treatment.

It is sad that it takes something like this to raise awareness, but thanks to this horrible event lots of people in authority have become aware how vulnerable and unsupported autistic people are. For me personally, it has hopefully been the catalyst to get some practical help at long last, so other victims of hate crime should know just how seriously it is taken by the authorities, and that some good can come of reporting the bullies in our society.

Footnote: this is the current state of play, but perhaps you would like me to enlarge or update this piece before going to press.

Tashi delek!

**Eric**

## In the beginning

haiku by **Cliff**

Mad person married  
stupid person: they begat  
civilization.

## letters to the Editor

**Hello,**

I have had two of your magazines up to now and I like them very much. I think they help me by just knowing I is not alone in a lonely part of the country where it's either being surrounded by very autistic people or getting dumped into groups by my social worker that if full of depressed autistic or ADHD people or "normal" people who think my noise sensitivity and "strange" behaviour is funny or frightening! I am very happy with your magazine. Thank you. I has never written anything before, this is a huge step for me. I would like in future to ask or make pen-pal advert, but not just yet. I is not ready. I would appreciate, like, feedback on what I write please. I like feedback and tips. I put in an envelope with stamp and my address but it's okay if you don't, I know people busy.

Thank you for your time,

**KJ**

*I have replied as asked, as I try to with everyone who submits a letter or article to me, Editor.*

**Dear Goth,**

thank you for your letter and sorry for not replying sooner.

My problem (with housing) is only now (after over a year) beginning to be taken seriously.

I have been trapped for the duration in a situation that, because of my experience, sensory sensitivities and response-based behaviour (living in the "here-and-now" and unable to entertain or understand objective-based behaviour which is directed by some or other aim in the future and is adopted by the "neurotypicals", pitching us directly at odds with each other) is entirely intolerable, but nobody would believe me that the problems I was experiencing were relevant and I was being blamed for my protests (and all associated behaviour). Story of my life, and scary! Only I thought that having a diagnosis would help people understand (I was diagnosed at the age of 48). It doesn't. At best they patronise (pity) you for being "disabled" and make no attempt to appreciate that not only are the problems experienced by the autistic entirely understandable and logical(ly reasonable), but that their "orientation" is more "in tune" with the world and the way all bodies respond in it!

I don't think we're quite the problem we're made out to be and I think people will eventually wake up to this. In my case the housing association (well, one member actually, who is the "chink in the armour") is now realising that it is mistaken in the way it

saw me (even with diagnosis!). I am treated as if I'm the problem but at least they allow for it now, so I'll put up with it until such a time as it is appreciated that they were a good deal more mistaken than they could have ever dreamed! No problem. That will take a good long time as there are precious few at the moment who are able or willing to see the massive benefits inherent in the condition and to demonstrate that what needs to change is not the autistic community but the attitude towards it! It seems to me that the more disabling symptoms experienced by the autistic individual are caused by his being exposed to a world that is not made for him (corrupted by the behaviour of neurotypicals) rather than being attributable to the way he would be if that was not the case and the fact that he is outnumbered — society is tailored to suit the majority. Of course there are exceptions but I do believe that we get incredibly "bad press", even from the specialists, and it grieves me very much!

Sorry about mistakes. I don't use a computer as the light "burns out" my eyes (rapidly gives me a headache, etc., and my eyes appear to be failing). I'm very tired now so must stop.

Keep up the good work. (And don't forget that you're not as "disabled" as other people tell you you are, or make you feel.)

Better not "go on" — I have a lot of trouble suppressing that desire!

Best wishes,

**Ann**

## three more letters to the Editor and a filler

Dear Editor

I think one of the problems the autistic have with speech is down to the OCD side of their personality, which shows up in perfectionism (doubt or lack of confidence) in the higher-functioning. With names your mind goes, “Is that the same sound, despite the difference in spelling or is it a different pronunciation?” With just words, your mind is thrown by syllables in the same way, mostly because of all the variations in vowels and vowel combinations, but also because of double letters, silent letters, archaic and foreign variations. To me it is no wonder we don’t speak until three or four, under these circumstances. On top of this, as Dr Cheri Florance points out in *Maverick minds*, we abandon speech for vision. This further confuses things because we take photographs of reality, not film it as a sequence of images. Like a roulette wheel, we see words click slowly round to form a sentence, whereas ordinary people don’t slow down this process and rush through, making mistakes just in order to say something and communicate to others.

Perhaps learning to sing would help close these gaps and make learning easier as has been found with other processing problems — stuttering, Alzheimer’s and Tourette’s for instance have all found this beneficial.

Yours sincerely

**Tony**

Dear Goth,

I would like to give Humbug Recipient something to look forward to. They mention on page 6 of Edition 88 that they are not aware of any politician from any UK political party who does not say that she/he subscribes to the idea of fairness and that this is humbug.

I would like to bring to the attention of all readers of *AU* a new political party that already has 65,000 members, despite only being in existence for eighteen months. It is called the Women’s Equality Party but is open to men too. Their leader Sophie Walker has a daughter who is autistic. Their policies include sorting out hate crime; help unpaid carers; Proportional Representation; ending economic inequality; flexible working and so on. They care about society and, in this case, I believe them, even though normally I am a cynic.

All Aspies should look at their website and watch this space.

Regards,

**Valerie** (woman, unpaid carer, Aspergic)

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## Travellers

by Glenn

We are all travellers in this life, so live this life with love, kindness, understanding, and an appreciation for things bright and beautiful.

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**If this does count as anxiety** please could you print in your magazine. If not then maybe a future issue may be suitable for such a thing.

Hello. My is **Natalie**, I have mild autism, I am 35 years old and I live in Kent. I am writing this as I was wondering if there are any counsellors or psychotherapists who read this magazine who could help me overcome my fears. Unfortunately I am on benefits so I can not afford to pay someone to help me, but as it’s a new year I am very determined and very

grateful for any help I receive for free as I feel my fears are like living in a real horror film.

My fears are needles, creepy-crawlies or animals that ever bite, sting or are poisonous, heights, pain, walking on snow and having a smear test.

I also have problems sleeping, though I don’t suffer from insomnia. I also keep washing my hands too much due to the phobias of germs as I like to be clean.

## Runaway horses

### part one

by Lois

I kept reviewing that day when I got “the news”, piecing together the bits of information I could remember, but my brain couldn’t remember it all. I couldn’t get the full picture. I could only remember bits of a jigsaw and someone had removed the vital pieces so I couldn’t make sense of the picture I was supposed to be making. Confusion lay all around me.

I knew I was probably in shock too. They say the brain goes into protection mode when you have a shock or an accident and this certainly felt like a near death experience for me. By not remembering it all the brain was supposed to be protecting me. But I wanted and needed all the information, now, and my brain was working against me, no matter how much I begged and pleaded with it to work properly, it kept its secrets locked away and it wouldn’t give up the key. My own body was working against me and I hated it.

Suddenly I hated everything about my body. If it had Asperger’s, it was doing me no favours. It had let me down. It wasn’t working properly and I was as mad as hell.

During those first few days after diagnosis, people kept telling me Aspergic people had slower thought processes because of a neurological difference. They seemed to be right, as try as I might my brain wouldn’t work any faster. It made me angry they were right, I raged inside. Even the clinician who diagnosed me had the cheek to tell me it would take me longer than “normal” people to process all this information. I hated her condescending tone; I hated her.

But as hard as I was trying to force my brain to work and make sense of it all, it just wouldn’t. Here was my Aspergic brain, if that’s what I had, slowly crunching away through the data when

what I needed was a super-fast rapid-processing computer of a brain that told me how to solve the problem. After all, I was a problem to be solved wasn’t I?

If I took too long to process this information then that would prove all those people out there were right. It would mean I had Asperger’s. Aspergic brains work more slowly so I couldn’t allow them to be right. I had to work faster, I had to try harder. Compute, compute. Work, darned brain, work.

But the information I was devouring from books and websites was exhausting me. I knew I was in a state of mental and physical exhaustion but couldn’t allow myself to stop. I raged on. I was riding a team of wild horses, bay horses, manes flowing in the wind, hearts racing, sweating bodies of pure gleaming muscle galloping flat-out whilst I whipped the reins hard, urging them to go faster and faster. I didn’t care if my body cried out for food, for water, for rest. I ignored it’s basic needs fuelled by the delusion that if I just got all the information, I could make sense of it all, I could come up with my own conclusions and I could decide if I had Asperger’s, not some fancy doctor with letters after her name who enjoyed delivering death blows. Yes, I would decide, no one else.

I was acutely aware of how my body was giving me signals every day I had Asperger’s, but I always excused them away — it’s the shock, it’s because I’m tired, this is why this isn’t making sense to me right now.

Obsessional thinking is part of Asperger’s and I kept excusing away my obsession to find out more, as being “natural considering the circumstances”. The fact that I couldn’t get this



team of runaway horses to stop, was rationalised by the thought that anyone in this situation would be doing the same thing. It turns out that many with Asperger's do exactly what I was doing but apparently, it wouldn't be common for neurotypicals to do it. The fact that I was so obsessed as to even ignore the basics of washing, dressing, feeding myself was constantly dismissed in favour of feeding my obsession. My obsession monster was getting bigger by the day and as it grew, it needed more food to fuel it and as it needed more, I worked harder and it got bigger and the less I could stop.

The clinician told me I had dyspraxia, common with Asperger's apparently. She said it would explain my clumsiness. I had always been told off for being a clumsy child and, on remembering these tellings off, felt a pang of resentment and frustration at my parents for not understanding I had a neurological difference. A sense of enormous relief flowed through me when I told my mother this and she apologised straight away, she didn't know, she said. I knew and it was okay, I could leave that one alone.

I had no problem accepting the dyspraxia, in fact I started to laugh when I noticed how many things I bump into in just one day, or how much I trip or stumble or drop things. I've lived in this house for twelve years and should know where my door jambs begin and end, yet found myself chuckling as I walked into the same door jamb twice in one day. "Ah ha, that explains it then," I'd think, "I have dyspraxia."

I usually get through two full sets of crockery in a year, berating myself for being clumsy. Now it made sense. I was forever watching the plates slide out of my hand. It was particularly annoying if the plate happened to be holding my dinner at the time and only last week I had to scoop up my jacket potato and coleslaw off the shag-pile carpet.

One plate and one bowl lost their lives last week. Forever consigned to the dustbin from dyspraxic hands. It was a relief not to hear myself calling me names for being stupid or clumsy but

to be able to accept, easily, this is dyspraxia and there's nothing I can do about it.

I continued to live a double life, telling people Asperger's wasn't a label, it was an explanation. An explanation of why I was the way I was. Yet even as I said the words coming out of my mouth I didn't believe them.

So much of the Asperger's made sense — my desperate need to be away from the world. How I hated talking to people and them talking to me. The clinician told me I had problems with social relationships and social communication and I had to agree with her, and what others told me too only added to the weighty evidence of how I appeared in the world. But it didn't make acceptance of the diagnosis any nearer.

I kept compiling the evidence, like a researcher researching some grand mystery, some long-forgotten case file, some unsolved crime. I presented myself with a compelling case why I had Asperger's but I saw the words and could see the patterns that applied to me but chose not to accept and make Asperger's a part of "me".

The high anxiety states I was experiencing daily were now leading me to panic attacks. Great! Another problem to solve. I raced through a book called *Asperger's and anxiety* by Nick Dubin. It made sense to me; it was like a breath of fresh air. It said I had a neurological difference. It told me that my brain had to work twice as hard to process information as compared to neurotypicals. This extra information processing the brain has to go through causes heightened states of anxiety. So if a real-life crisis situation comes along, like the one I had found myself in for the last five months with impending redundancy, then my anxiety levels would naturally go through the roof.

Slowly, more began to make sense and I started to see how my behaviours and thought patterns were along the autistic spectrum.

*The final part will be published in July, Editor:*

## Uncertain futures — adults living with autism

by Malcolm

I was invited to take part in a research project in collaboration with the Institute of Neuroscience at Newcastle University early in 2016.

My experience of ASD is a personal one. I was diagnosed with Asperger syndrome at 52 years of age. This was prompted by my youngest daughter being diagnosed with ASD the previous year. My role was to be a facilitator along with two colleagues who also had different experiences of ASD but were neurotypical people.

The background to the research was based upon the premise that very little research has been devoted to autism in adulthood. Our study wanted to focus upon worries and fears for the future to further inform this body of knowledge.

The structure of the groups was fairly simple. Two groups in Scotland and two in Newcastle-upon-Tyne. The former involved overnight stays. Typically, approximately twelve adults living with autism were invited to a venue for two hours to give their personal account of anxieties and concerns for their future. The group also invited parents and carers along to support their son, daughter or charge. The format was kept simple, promoted discussion and allowed members of the group to leave if they were overwhelmed or distressed at any stage.

Despite the fact that professionally I was a retired registered nurse and also had served with armed forces as a Reserve Forces Nursing officer, I felt quite anxious about taking part in the project. Perhaps this was my own anxieties coming to the fore, ruminating whether I would be a help or a hindrance to the project. Could I actually do this? I had reservations, but went ahead because my daughter was 18 years old this year and I wanted to hear the views of young adults too, in order to clarify some of the issues that my child may feel but might not actually

articulate. In retrospect, I am so glad that I did take part. Anything which informs the paucity of research so far to help adults with ASD, our fears and anxieties and heightens awareness of the condition itself, can only be beneficial to our children.

Anecdotally, I remember more females turning up than males. This surprised me, given the supposed diagnostic ratio of 4:1 males to females with ASD. Women seemed to be more open about sharing their worries. I wondered if it was that despite living with ASD, they socialised in a different way and seemed more at ease confiding in others than the male participants.

Some of the results were not surprising, however, I was heartened to learn that some of the statistics relating to autistic people and employment were not borne out by this cadre. The figures we had split between 50% of participants being unemployed and approximately 50% who were in work or had retired from employment. The figure banded about is 15% in work.

One of the other discussion points that I could relate to was that of “minimisation”: “Being told that your autism “doesn’t count” or isn’t severe enough”. In other words, “You don’t look autistic so you can’t be” — it is awareness which would prevent such crass remarks.

Now this research was carried out a full six years after the *Autism Act 2009*. It was also a full year after a new statutory guidance by HM Government in 2015, requiring local authorities and the NHS to implement a six-point plan in order to support adults in their areas living with ASD.

It seems to me that not only public awareness needs to be heightened, but moreover the

## an article (continued), a notice and a poem

plethora of professionals that we can expect to meet in our adult lives need to be much more informed and much more aware. Autism is a spectrum condition.

Personally if I was writing a school report, it would read thus about the strategy: “Laudable aims and wants to be seen to be doing well. The reality is of course that it really is no good employing ‘Blind Pugh’ to drive the strategy. He can only imagine what autism looks like and can’t actually see it. No autism strategy without autistic adults . . .”.

If sufficient material is sent in, the theme for July will be **fiction** — why do you read fiction? Why don’t you read fiction? What is the difference between a story and a novel? What’s the difference between legend and myth? If that’s not a popular choice of theme, how about **hoarding, collecting and other activities that some people try to stop us doing?** Again, feel free to take this idea to any related subject you want, or to a completely different subject — it’s your magazine! 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 are ideas for new themes, and artwork. Perhaps you’ve been to an event: why not write about it? Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

**I received my Asperger’s diagnosis** in 2011 at the age of 46. During a recent stay in my local hospital’s mental health ward, I wrote a very short piece about Asperger’s and me, shown below. I have shared the piece with a few people so it makes sense to send you a copy.

Happy New Year,

**David**

Imagine needing order in a disorderly world.  
Imagine creating order, and being laughed at for doing so.  
Imagine needing precision in an imprecise world.  
Imagine being precise, and being told it is often unnecessary.  
Imagine needing structure in an unstructured world.  
Imagine creating structure, only for people to tear it apart.  
Imagine needing words to have their literal meaning.  
Imagine taking words literally, only for people to consider you stupid.

Imagine order is innate, and you have to work out when order is not required.  
Imagine precision is innate, and you have to work out when precision is not required.  
Imagine structure is innate, and you have to work out when structure is not required.  
Imagine taking words literally is innate, and you have to work out when the meaning is not literal.

Imagine becoming anxious when you see the “Random” button on your CD player.  
Imagine becoming anxious because someone gives you £10 when they owe £9.60.  
Imagine becoming anxious when you see fiction and non-fiction books mingled.  
Imagine becoming anxious when you are told to wait ten minutes and it is eleven minutes and counting.

If you can imagine this, then you can begin to imagine my world.  
Welcome to my Asperger’s world.

## My journey with George Orwell

by Philip

This story is about how the extraordinary journalist, political satirist, and social critic Eric Blair — popularly known as George Orwell (1903–1950) — influenced my life as a positive role model and personal hero.

I discovered George Orwell at school when the author's book *Animal farm* was included in our syllabus for English literature. *Animal farm* is a political allegory about totalitarian rule of a farm by pigs. Shortly afterwards, I read his books, *1984* and *Down and out in Paris and London*. The latter book is essentially Orwell's personal investigative journalism about life on the edge of society in boarding houses, known as "spikes".

I perceive Orwell as an individual with extreme integrity and passion for writing. Orwell "walked his talk" and used his writing to make people more aware of social injustice and hypocrisy that gripped England at that time. He was such an open-minded intellectual that he called himself a "Tory anarchist".

Orwell shared his intimate experiences with us — on subjects ranging from bed-wetting to masturbation at school — and he placed no

limits on his pursuit for truth. Incidentally, at the boarding school I attended, pupils held regular "masturbation contests" which was shocking to me as an innocent eleven-year-old boy.

The biography of George Orwell by Bernard Crick explains that Orwell's friends and family ridiculed him for his literary ambitions, but with sheer dogged persistence, he succeeded against all odds. He who laughs last, laughs longest! Even today, many literary snobs are highly critical of Orwell's writing style.

I related to many of Orwell's experiences, from being bullied and caned at a British boarding school, to being the poor boy (at school, university and later in a top international accountancy firm). Both of us support underdogs and victims of injustice.

I lived in London (on and off) from 1982 to 2003, and during this period, I took the George Orwell "tour of Islington". I visited one of the houses that Orwell rented with his wife in 1944 at 27b Canonbury Square, Islington. Coincidentally, I lived in Islington and Hampstead, both places where Orwell had lived.

In the year 1999, I worked in the Isle of Man for a private bank, but unfortunately I had to resign my board appointment because the shareholders insisted upon money laundering. When I lived in the Isle of Man, I wrote a book entitled *The theory and practice of oligarchic manipulation and control* — influenced by the forbidden book mentioned in Orwell's *1984*.

In 2003, I migrated to Northern Thailand because I was unable to survive in England, despite being a chartered accountant and MBA. Occasionally, I travelled to the Myanmar border to extend my Thai visa. I learnt that in 1924, Orwell served as a police officer for the Imperial Police in Burma, but later he resigned to start his writing career. Two excellent books relating to Orwell's time in Burma (Myanmar) are *Burmese days* (by George Orwell) and *Finding George Orwell in Burma* by Emma Larkin (investigative journalism).

In Mandalay, Orwell developed a reputation for not fitting in. He was described by his colleagues as "sallow-faced, tall, thin, and gangling, whose clothes, no matter how well cut, seemed to hang on him". In Emma Larkin's



## an article (continued) and a filler

book, Orwell is described as “socially inept, preferring to read alone voraciously”.

Orwell developed a keen sense of the British class system during his school years. He was always perceived as the poor boy in the class of rich kids from prestigious families, and his alienation was compounded by perpetual ill-health, especially respiratory problems, which prevented him from excelling in sports. So, Orwell developed into a social misfit with interests ranging from nature and politics to black magic.

In November 2011, I discovered that I have Asperger’s syndrome after reading an article in my professional accountancy magazine, while I was living in Phnom Penh. This inconvenient realization caused a massive crisis in my life, but I am getting to understand myself much better now.

My mentor wrote to me, “I think you now know and wish you did not know you have AS. You have stopped continuing in the old Phil way as you are not the old Phil. You are new Asperger’s Phil and have not lived as an Aspie — only as

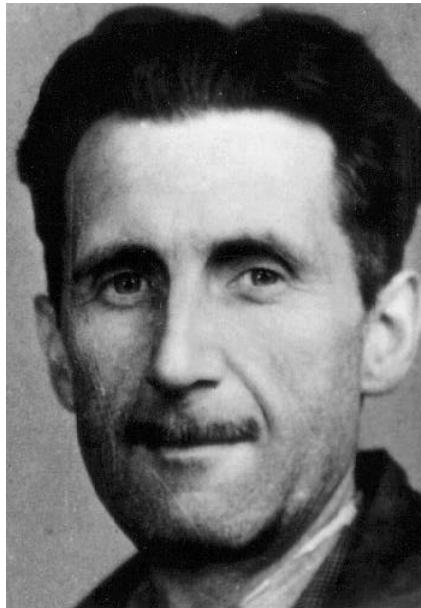


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an Aspie denier with a veneer of normality. Some people are set free by a diagnosis — to be who they really are. Some have a down-time to process this change — and come to terms with it — as you are. You will soon work out what is your best way forward — but living out as an Aspie as you are aware, is also a problem as people will then ask you questions about it and with AS being a communication problem you will struggle. There is no right answer. Let time do its work . . .”

Despite my identity crisis, I have become aware that many of my friends, heroes, and favourite artists also have

Asperger’s syndrome. Autism specialist Professor Michael Fitzgerald says in his 2004 book that George Orwell fitted the criteria for autism spectrum disorder, so Orwell probably had Asperger’s syndrome. In Orwell’s autobiographical essay, *Such, such were the joys* (1947) there is much evidence of his social problems and resentment about the way he was treated at boarding school.

Freedom, integrity, and individuality are the most important qualities in my life, and George Orwell embodies these characteristics. Ultimately, the journey as an outsider with a passion for identifying and expressing the truth are concentrated in the Orwellian slogan, “The price of freedom is insecurity.”

Other influential Aspies in my life include Albert Einstein (for his essays about capitalism), Nicole Kidman (*Eyes wide shut*, directed by Stanley Kubrick), David Byrne (Talking Heads) and Stanley Kubrick (*A clockwork orange*). However, my favourite lifelong influence and guide is George Orwell (Eric Blair), who was living way ahead of his time. *I love the man!*

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Bearing grudges, having regrets or feeling sorry for oneself for traumas of the past is a total waste of precious energy, just as it is to worry or to have fears for the future. Yesterday is history, tomorrow is mystery, today is a gift — a present of the present. Your energy used as a present in the present — in the now — is totally potent and can manifest truly magical results!

from Tracey

## Realise your talents and pursue your dreams

by **Melissa A Joy**

Have you ever dreamed of achieving something, but were too daunted by the challenge or couldn't focus and ended up waving the white flag of defeat? Whether your talents are in the creative arts or even in science or engineering, you should never lose sight of them.

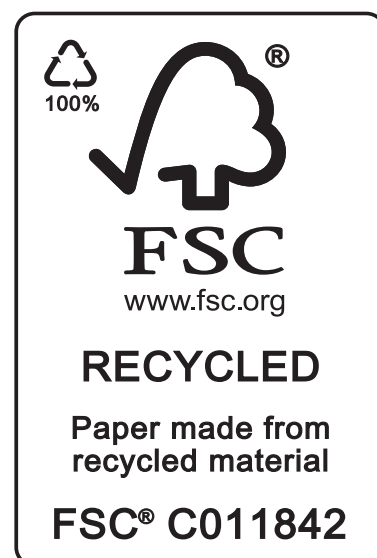
I was diagnosed with Asperger syndrome at the age of 26, and after much toiling over the years, I've accomplished my dream of being a published fantasy author. It has been my dream since roughly the age of 13: I believed there was nothing else out there for me, that was what I wanted the most in life. It took me until 2016 to finally get my debut novel — *Keys of the origin* — out into the world, but it was a rare stroke of luck that got me out there sooner rather than later. I was discovered by someone who had started a business for writers' services and publishing, and as I needed some experience in other fields of literary expertise (with a view to becoming a proofreader or editor), I joined the company as a volunteer. I was then offered a chance to have my book published, because if I were only to follow the traditional publishing route by sending letters to agents and publishers, I could be receiving rejections for many

years, and at the age of 30 I wasn't prepared to accept that. I'd worked so hard for so many years on my dream of being a published author that I couldn't say no to such an opportunity. I saw it as a stepping stone, a means to an end that I was so desperate to accomplish.

Self-publishing doesn't suit everyone (and to be honest if traditional publishing was easier to get into I'd have taken that path instead) but what it does offer is a chance to make a name for yourself. Admittedly there are small presses out there who aren't all they claim to be, but there are a lot of good ones out there as well: you just need to do your research to unearth all those that throw up red flags and discover the ones doing honest business. In most cases it can be a bit costly, but it all depends on how much effort you're willing to put into achieving such a dream. I made good use of social media with a basic website displaying excerpts of my writing, and it was in 2013 that my current editor and publisher found me on Twitter, and he liked what he saw. That's how I got involved with his company, Blackheath Dawn Writers. Your own dream may not even be in writing and publishing, but I spent seventeen years pursuing mine, and now my

first book is available for sale worldwide.

So many of us with Asperger syndrome or autism have strong desires to succeed, but end up throwing in the towel when we become frustrated with our efforts or daunted by stepping out into the unknown. I have suffered with anxiety and depression for many years now (and I'm still not out of the woods yet), but after having my book published and achieving a bachelor's degree, in English literature and creative writing, I feel more confident than I did. I believe we are all capable of great things if we utilise and develop our talents, and it doesn't matter how many small steps we have to take in order to get there. Don't give up on yourself.



## 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 autistic subscriber 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](http://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](mailto: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.
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- 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 other NAS publicity about that book, 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.

## **Autscape 2017: An *autistic* conference**

King's Park Conference Centre, Northampton

Tuesday, 8 August – Friday, 11 August 2017

An annual residential conference and retreat organised by and for autistic people.

This year's theme is *Autism in context*.

What we offer:

- An autistic-friendly environment
- To meet other autistics with or without a diagnosis, including those with Asperger's
- Non-autistics are equally welcome
- Workshops and presentations
- Autistic-friendly leisure activities including a sensory room, *Sparklies in the dark*, trampolining, crafts and retro computer games
- An accessible residential conference centre
- Sports facilities close by
- Day time childcare included

- Full board – three meals a day plus tea and coffee breaks – included in the price
- Travel to and from venue arranged from Northampton train station (for an extra fee)

Registration will take place via the website and details will be posted there.

Further information regarding the conference, registration and attendance fees is on our website:

**<http://www.autscape.org>**

Email enquiries: **[info@autscape.org](mailto:info@autscape.org)**

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