

Produced by and for autistic people

# Asperger *United*

Edition **88** October 2016

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# 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  
393 City Road  
London  
EC1V 1NG

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 **7 November 2016**

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

I again had a wonderful time, meeting many of you at Autscope, which is my most restful and stress-free time of the year.

I will look forward to more new faces next year, and I hope that events like this will continue to grow and spread, as this will both reach more of you than is currently possible and show other organisations how it's done. The world badly needs to know how to accommodate the huge variety of people on the autism spectrum, and, for that matter, the huge variety of people in the world — it's not just autistic people who are left out of planning, after all; many "neurotypical" people are left struggling as well.

This year's theme at Autscope was identity, so this is an appropriate moment to point out that less than 3% of people actually are neurotypical — most have some sort of neurological difference, but seldom quite as many as come together in autism.

I have seen a rise in groups not for autism but for the neurodivergent, which in principle is everyone who isn't neurotypical, so that could be 97% of the population. Part of me feels it's rather cruel to exclude that small minority, the "normal" people.

So, my identity is "take me as I am, I'm a nice person". Maybe it's towards people who don't try to be nice that we should show some discernment,

**the Editor**

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## the sensory edition — suggestion for next issue on page 13

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## Sensory differences are a very interesting . . .

by Tom

Sensory differences are a very interesting

<<rumblerumblerumble crash>>

topic. I would venture the main sensory difference

<<bang>>

between me and the rest of the

<<BOOM!>>

Er . . . where was I? The rest of the

<<BOOM!>>

For f . . . THE REST OF THE WORLD . . .

There.

The main difference would be my sensitivity to

<<bang bang bang wrooomm>>

(sigh) sound.

A short while ago, there were renovations near my home that apparently necessitated Diesel engines running continuously.

<<rumblerumblerumblerumble>>

Since at the same time,

<<rumblerumblerumblerumble>>

there were renovations at my place of work,

<<boomdrillcrashdrriiillboomboom>>

that meant that I went from one noise

<<rumblerumblerumblerumble>>

to the other.

<<boomdrillcrashdrriiillboomboom>>

When one night a few local youths decided

<<WRRRRROOOOOOMMMMMM>>

to ride their extraordinarily loud motorcycle through the street where I live, I lost it and went into full melt down. Fear of death, panic, exhaustion, severe depression. Not that I did anything drastic, or got into trouble, but it was deeply distressing.

From what I understand, I do not necessarily have more acute hearing, but I do seem to have a much lower tolerance than (neurotypical) others for ambient noise. At work, I have seen people conduct meetings and even phone calls with hammering going on. In such a meeting, I needed all my concentration to follow what was going on and felt pretty much exhausted afterwards. The noises I described would for most people be annoying or even infuriating, but caused me to — briefly — experience extreme depression, which is quite a bit more serious than “infuriating”. Still, noise is a universal irritant, since I have been able to explain what daily life was like for me by referring people to times they experienced a noise they found irritating. People do feel the same way in these instances: defenceless, unable to relax and feeling compelled to anticipate the next episode of whatever’s bothering them. Of course, for people with autism, it’s rarely just one irritant at a time, but the simile seems helpful for neurotypicals (those suffering from Nutter’s syndrome, in other words — that was a joke) to understand the elevated level of stress (or general arousal of the nervous system) we live with.



That I seem to have a lower threshold for external stimuli before they bother me makes perfect sense. Autism, after all, is a sensory disorder, specifically the brain's processing of inputs (of which sensory inputs are one example, but thoughts are another) and assigning importance to them — that is, something other than entirely all right, or deeply, life-threateningly alarming. That is how it feels to me: a noise quickly becomes all-important, making it impossible to devote thought to other things (like eating or even walking). It feels to me like I lack an instinct in being able to classify a thought as “ongoing, but not that important right now”, which would be the exact category that noise would fall into. I am capable of assigning a relative importance to something, but it takes a considerable and conscious effort. That limits the amount of input I can handle before emergency systems kick in (generally resulting in me ignoring — or doing my best to ignore — something until it can no longer be ignored, with all the consequences that entails). I have found it nearly impossible to relax when there are people around (with one or two exceptions) and I think that has a lot to do with the sound they make, although social matters play their part as well. No other members of my family have a diagnosis, but that does not mean they shouldn't have: I can vividly remember how annoyed my brother could get at a small noise or movement (like me wiggling my foot).

When I observe animals, most seem unbothered by noises emanating from sources they can't see, even if they are very loud. When something comes close, though, and thus becomes threatening, any little noise is enough to scare them. Humans seem to have a similar instinct, being able to ignore noises going on around them. Up to a point, at least. Maybe there is a difference in the perception of danger, coupled with, or caused by, the sensory differences. Studying how noise impacts animals could be very interesting in its own right, but also for people with autism. It's one thing to not see a reaction in an animal, it's quite another to ascertain that stress levels remain the same. Maybe unravelling the mechanism that governs perception of danger could benefit autism research.

## Venturing through the land of the triclops

story by **Angela**

There it was. A triclops. It's red eye made contact with mine, and I froze, caught in deep fascination with this preternatural creature that could hold back ten-tonne lorries with its fiery glare.

Two blinks later, and I heard the fearsome roars of metal beasts, roars that would rise to a terrifying climax before receding into the distance.

I broke out of my trance and returned to running, with my sweat-soaked clothes clinging against my skin and confining me within their snake-like seams.

The territory of the triclops is one of expanses of grey, of straight lines and ugly blocks of colour that hurt to look at, of an inescapable bombardment of noise. They stand, lofty and unperturbed, above the cacophonous lands that they rule over. It is a place that must be passed through in order to reach “my” woodland haven.

Reaching the woods brings a thrill of relief. I love the sense of wonder and enchantment at the sight of sunlight shining through leaves, at the energising rush of wind whispering through the trees and tickling my skin. I leap at branches and laugh and cry and sing and dance and soar on waves of elation as my attention is captured by a myriad branches forking and forming intricate patterns that teem with overwhelming aliveness.

The siren calls of birdsong try to seduce me into staying in the woods forever. I have to resist, to return to the land of the triclops, to a land of responsibilities and sensory overload and attempts to join in with pointless social customs and tedious smalltalk that only serve to intensify the constant feeling of loneliness.

## Foolish letter

by Tony

Dear Wills,

I'm not sure if I'm going to write this letter or not, so if you don't get it, that's why. (Write and let me know in either case.)

I don't know what the weather is like there but it is the same here. By the way we might come up there on holiday. If I don't see you when I arrive, it's because I've decided not to come. We were going to visit last year too but as you hadn't moved to where you are now because you were somewhere else, there didn't seem much point. How's the wife? No, not yours, mine. (If you can see her from there, you've got bloody good eyes!) We were abroad last year — The Paris Hilton! We even talked to her but she didn't recognise me, even though we'd never met.

As I lie here writing this letter, I see Mary is in bed beside me, which is strange as my wife is called Alice. Oh yes, now I remember — it's my cousin Mick's wife, who's come to visit and I'm in the wrong bedroom again. My eyes are not what they used to be — I think they used to be my armpits, which could explain why my sight stinks. Children grow up so quick nowadays. Last week, Donald, my eldest, was fifteen and this week he's

sixteen. (Birthdays — who'd have them, except people who are older.)

My mother would like to say something but as she's tied and gagged in the garage, that would be difficult. We tried to give her a respray, so we could get her deported as one of those illegal immigrants. (She always wanted to see the Taj Mahal, so we thought it would be a nice Christmas present for her but she wouldn't hear of it. "You're too generous son," was all she said as I dragged her screaming and kicking outside. "No Turkey for you this year!" I said (or India for that matter).) "Now where's that spade?" (She always wanted to be buried beside my father but I think she was expecting to be dead first. Still, nowadays, you can't always get what you want). Must go now. Someone is knocking at the door and I think it is the police collecting for Charity and as she isn't here, I'll have to answer the door myself.

Your friend,

**Pope Pius the Tenth** (only kidding — Pope Pius the Eleventh!). No I'm fibbing again, it's just me as you'll recognise from the photo I didn't send.

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Hello *AU* readers,

many contributors to *AU* state in some way or other that they have low incomes.

I am not aware of any politician from any UK political party who does not say that she or he subscribes to the idea of fairness. Humbug.

These same UK politicians are responsible for the introduction or the maintenance of umpteen regressive taxes. And as your dictionary (an

independent source) will tell you, a regressive tax is, "a tax taking a proportionally greater amount from those on lower incomes." Or, to put it another way, it is a tax which takes a proportionally lesser amount from those, like all UK politicians, on higher incomes. And that is the problem with democracy — no matter who you vote for, politicians get in.

And that ain't fair.

**Humbug Recipient**

# Pen pals

## Pen pal number 227

Hello, my name is Rebecca.

I was diagnosed with Asperger's when I was 14. I am now 19. I live in London.

As well as Asperger's I also have an anxiety disorder called selective mutism, which I've had for as long as I can remember.

I like to watch science-fiction and historical drama television shows such as *Doctor who?* (series 1-4), *The Tudors* and *Spartacus*. I also watch the soap opera *Eastenders* as it is enjoyable at times and I find that it strengthens my understanding of neurotypicals in lieu of actually interacting with them.

I am also interested in history so do like to watch any documentary that catches my interest.

I thoroughly enjoy reading and will read almost anything, but my favourite genres are historical fiction and fantasy. I enjoy reading about the Tudors and various Plantagenets most of all. My favourite fantasy series to date is *A song of ice and fire* by GRRM (also called *Game of thrones* after the television series).

I am also interested in Greek mythology and the Percy Jackson series by Rick Riordan has a special place in my heart.

I also like to write, particularly fanfiction.

I hope to hear from someone with similar interests.

## 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.

*Twenty-one pen-pal adverts have been held over for publication in the next five issues, Editor.*

### Pen pal number 228

**I'm Marinus**, over in Vancouver, British Columbia, Canada. I'm 68 and male. My autism is of the invisible-on-surface sort. I look and sound quite normal, except for occasional bad patches. But my stimulus oversensitivity and lack of affect are very strong, incapacitating actually [autism basically destroyed my life, as I am now an utter hermit, and poor]. But if isolation has its obvious painful aspects, it is also a gift, giving one true mental independence and emotional-bias-free self-knowledge.

I must warn that I have been found abrasive, for what that's worth.

I read a lot of psychology [in self-defense!]. Not the lowest self-help level, and not academic top-level, but that mid-level typified by authors like Oliver Sacks. I also read poetry [ie. Wallace Stevens], general science [the UK publication, *New scientist* is a delight], and fantasy/science-fiction. I actually have a sense of humour too [no, really!]. I invite letters from anybody who reads seriously [non-fiction that is]. Your age/sex/beliefs are immaterial to me.

Hopefully,

**Sub' [marinus]**

Hang loose but don't fall off.

### Pen pal number 229

**Hi, my name is Michelle.**

I am 25 years old and live in Luton with my mum and 13-year-old sister. I have mild, high-functioning, autism which I was diagnosed with at the tender age of 5 and I went to a mainstream school.

I studied performing arts at college and the next course I want to study is theatrical makeup. I have performed in local amateur dramatic shows and musical theatre is one of my big interests.

My other main interests are going out shopping, social events, parties, gigs/concerts, fashion, beauty, and I am obsessed with social media.

I would like my pen pals to preferably be round my age group, to live in my area, to be outgoing and to have familiar interests to me, particularly anyone who is a fan of Union J, as I think music tastes play a big part in who you bond with people over.

I look forward to hearing from you.

### Pen pal number 231

**Caroline**, 36, North West; recently diagnosed.

I enjoy alternative music, historical true crime, kitchen-sink British films, *Steptoe and son*,

### Pen pal number 230

**Hello, my name is Luke,**

I am 25 years old and I was diagnosed with Asperger syndrome when I was 19 years old.

I am a prisoner and would like to write to someone who is on the autism spectrum and with similar interests.

My interests are the Avengers, biology and physics, formulae, mathematics, *Doctor who?*, *Call of duty* and robotics. I enjoy listening to Michael Jackson, Johnny Cash and Status Quo. My other interests are being helpful towards others, being supportive and kind; I am very polite.

My ambitions are to go to university and study artificial intelligence and how to build and programme robots. My future business venture would be to design and build robotic equipment for the fire-fighting services.

I'd like to have someone to write to and look forward to speaking to you.

history, theatre and lots more.

I would really like to write via post, as I love writing and receiving mail.

Look forward to hearing from you!



Hi there,

my name is Callum,

I believe I met the Goth at the first annual Autistic Pride Picnic in London last year and at another time at a conference at the Lincolnshire Autistic Society's conference at Petwood Hotel, perhaps among other meetings.

I wanted to share with the magazine the arts-based platform for autistic people.

It is expressive, fun and free.

I have had it live for a month and am still working towards a thriving creative community — but I know it's out there!

So may I please ask for its inclusion in an article?

If you head to

**[www.spergy.org](http://www.spergy.org)**

then you can see the site so far.

Also, I'm on Twitter at the link below:

**<https://twitter.com/spergycommunity>**

And Facebook at this link below:

**[https://www.facebook.com/spergycommunity/?ref=aymt\\_homepage\\_panel](https://www.facebook.com/spergycommunity/?ref=aymt_homepage_panel)**

I am a performance poet and have recently released a book of my poetry which can only currently be purchased in person or by post.

*Are readers happy to have web links in articles in Asperger United? Although very few readers have a computer, more and more of you have smartphones — I can tell from the number of letters I get which are sent from phones rather than computers, so I'm guessing you are happy, but let me know. And yes, I'm working on a phone version of AU, just don't hold your breath waiting for it!*  
Editor.

## Building an autistic community

Got something to say? Then come to **AutSpeak!**  
Organised by autistic adults for autistic adults.

Date: Thursday, 12 January 2017

Time: 18:30-21:30

Location: ArtsadminToynbee Studios  
28 Commercial Street  
London  
E1 6AB

A winter evening event for adults on the autistic spectrum featuring a lively programme of stimulating talks, discussions, an open mic session and other entertainment.

Booking essential. For bookings or more info (including event schedule) please contact

**[autspeaklondon@gmail.com](mailto:autspeaklondon@gmail.com)**

or see our Facebook event "AutSpeak London".

If you have any queries on the day please call Joseph on **07792 132 150**. You can also use this number if you are lost on the day.

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## 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.

## letters to the Editor

**Dear Goth**

I note the theme for October is sensory differences.

My sensory difference is I am unable to wash. If I do I itch all over and it's most uncomfortable. I have tried all different soaps, even just water, to no avail. I hate wearing clothes and even in winter I will wear shorts.

I don't smell, it's like my skin is self-cleaning. May I take this opportunity to thank you so much for *Asperger United*. It has helped me so much to read other Aspies' struggles which I can relate to.

This is my family and I'm not alone. I can cope with life so much easier.

Yours sincerely

**John**

---

**Dear Goth,**

regarding your suggestion on sensory differences, I wonder if anyone else cannot bear the sound of e-cigarettes? I hate the sound they make when vapourising, as it really makes me cringe. It is almost like someone scraping a fingernail over a blackboard. Also, I cannot bear yappy dogs and their yappy owners. I do wish neuro types could be quiet or do they have to make such noise in order to make themselves heard? I pity them for not knowing the great haunting beauty of silence. I crave the open moorlands here in Staffordshire and being able to heal myself, away from noise. Does anyone else have the same need for quiet in order to recover?

**Nick**

**Dear Editor**

I was interested to read John's article on page 11 of the July edition of *AU*, as it is becoming more and more difficult to find articles from people close to my own age (68). All the articles and pen-friend applications seem to cater for a much younger audience . . . .

John's article, headed up *It's all in the mind* . . ., struck a chord with me, as I too find it easier to put on paper what I want to say, and find it difficult to verbalise face to face what I want to convey, which can be very frustrating and distressing, especially if it is something I feel strongly about.

I did have an article printed some time ago in *AU*, but haven't written for a while, as isolation does make it quite difficult for me to summon up the courage to reach out to others, having tried and failed on so many previous occasions, and the older I get, the harder it gets to break the cycle . . . .

Like John, I was good at my job (medical secretary) but struggled with social, inane "chit-chat" with work colleagues.

**Sue**

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**Hello all cynosures,**

if you are on the autism spectrum, then hello, I am likely "talking" to you.

Many decades ago I came across the phrase "Hell is other people". Succinct.

In the July edition of *AU*, Pikachu Murray introduced me to the word "cynosure". The word is new to me. A cynosure is a person that is the centre of attention. Succinct.

As an individual with autism, I have been a cynosure, without wishing it or intending it, every time I come into contact with other people that I do not know. Other people can sense that they are in the presence of someone not like themselves. And whatever your difference is, the different, all-natural cynosures, will have experienced hell from other people. Why is that?

**Fellow cynosure**

Dear Goth,

I only just thought of this, near the end of the month. Certainly too late for the *Misunderstood* issue, but may also very much relate to the “sensory differences” issue. I reckon you, Mr Editor, are about to dive deep into that confusing realm known as perception, though you might have done so before, and so you should brace yourself (again?) for the likes of: “This perfume was pleasing to that person — but I had to leave the room!”, or “The music was loud rock music and, though they danced to it, I had to cover my ears!”, or, if you’re lucky, “I can hear dog-whistles and birds flying over me, which they can’t!”

Got all of that so far? My point is, on both topics, basically these examples: “most” people can’t, and “some” people can:

- hear outside of 20 Hz to 20,000 Hz, or can use echolocation;
- see ultraviolet or infrared, or can see other so-called “invisible frequencies”;
- taste air, or fluoride in water, or if a food has been cooked with utensils made of iron or not;
- smell hormones, or racial differences, or whether someone is moving closer or away from them.

Now, even this tiny example of course leads onto way too many other topics . . . so I won’t start them here. Everyone is different, has been raised differently, exists in a different environment — yes, even “identical twins” can be very different.

Guess what? This further augments the “brainwaves” fact, that I say that: autism is just the “disability” of being burdened with sensory ability which “normal” people can “grow out” of. This “sensory” business is said by so-very-many “autistic” campaigns . . . go and check them if anyone does not believe me . . . and the

reason why no-one believes that simple premise . . . is because they have never compared what an autistic person knows versus what they themselves cannot perceive . . . at that moment.

If NTs want to hear, see, taste, smell . . . whatever they can’t perceive is “upsetting” an “autistic” person, at that moment, then they have to use a machine to do it. Or use an “animal” to do it. Alas, even when such things are observed, it is less likely understanding which results, but more like: “Oh, that’s funny! They seem to be reacting the same way! I can’t see/hear/smell anything! . . . so just stop acting so stupid!”

Lastly, now a different approach. I only venture this to (futilely) seek confirmation over another curiosity. Are “autistic” persons more likely to perceive “gobbledegook”, especially when under stress? We stand there and really try hard to listen to or see what we know that we are listening to or seeing . . . but sometimes or suddenly, it is as if it is not there, or is made alien, or erases itself, or it is mixed up. As you can see, this leads onto other “disabilities” (eg., dyslexia, synaesthesia) but — irritatingly? — all such confusions only further prove the validity of the “brainwaves” statement that I insist upon. If we lack the capacity, then we can’t capture or relay something in that manner — it’s as simple as that. We may instead capture it in what is “socially” defined as “the wrong way”, such as “seeing how things feel”, or whatever other descriptions are attempted. You may liken neural links and brainwave frequencies to a physical arm or an ear, and so then the lack of that link or capacity is defined as the “disability”. And if you have the arm or ear growing in the wrong place, then that is also defined as a “disability”, or even as “nonsense” or as “madness”. But what makes the application of this not at all simple, is that it is different for everyone. The smell of a perfume, a certain colour, a musical tone . . . we each have something which “incapacitates” our abilities that is different from the defined normality.

That’s it. Ciao.

Signed Piiiiiii-Chuu

## letters in response to Richard

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**Dear Goth,**

I am just writing a quick plea in response to Richard's very good feature article *It was just an honest mistake* . . . on pages 4-5 of this month's *Asperger United*. I found his article very interesting and well written, and I enjoyed reading it very much. I do have some difficulties understanding intentions, and I believe Richard would never have meant to offend or hurt anyone in the ASC community by any of his comments, therefore I am not allowing myself to be offended or hurt. However, I would just like to say that I got a bit panicky about the comments he made about PDA (pathological demand avoidance) which seemed to suggest it does not exist or should not attract focus or time from the NAS and other organisations. I am sure Richard cannot have been suggesting it does not exist or that the NAS should not waste time on it, but my difficulties in comprehension mean I am a bit unsure. I would like to apologise to Richard for this, and hope he does not take offence over my confusion. It can be very irritating when someone seems to focus only on one small part of what you were saying (this has sometimes made me feel like I cannot say anything at all because some small insignificant part of it will attract criticism). I really don't want Richard to feel like this, please don't. We cannot possibly see everyone else's perspective all the time.

When it was believed I had Asperger's it was a very difficult and confusing time for me. I have vastly different difficulties from many people I know with Asperger's and from the Asperger's assessment criteria (whether you agree with these or not). It has been the biggest relief of my life to self-diagnose myself with PDA. I cannot get a formal diagnosis however because I am an adult, and this is very inhibiting. I need help with virtually every aspect of my life (but do not get it) because of extreme unimaginable (hence 'pathological') anxiety over demands. This is not just demands made by others, it is demands made by myself on myself. This can include every single thing I do, even speaking, moving my eyes, hand or head usually feels like a demand and this causes almost perpetual distress.

I think every single sort of ASC, and there are surely more of them than we currently know about, needs as much recognition and research as possible in order that more ASC people can receive the support and understanding (including self-understanding) they want or need. I do not feel comfortable with psychiatric labels, but without the research done by Phil Christie and Elizabeth Newson (and many others) into PDA I do not know how I would have proceeded in this life. I think there is a danger, if we do not recognise new and marginal forms of ASC as really existing, being the way real people experience the world, that some people in the ASC community will be made to really suffer. I do not have the sort of brain which is built for doing research into or campaigning for greater recognition of all the different sorts of ASC — I am good at other things instead — and I am so grateful to those people who do have that sort of brain for putting their talents this way.

My plea is to anyone involved in the campaigning for or research of PDA and indeed any other marginal or yet underresearched/unrecognised but research-supported form of ASC. Please please please please please do not stop! I do not know what I would have done if I had not found out about PDA. I would also make a plea to all *AU* readers to try to be tolerant of others who know their own form of ASC is different from what they have been diagnosed with. As all readers will know, it is hard enough explaining to neurotypical people how you differ from them — especially when you outwardly "look" like them — and it is just as hard trying to explain to someone with Asperger's how you differ from them if you have PDA, and vice versa I am sure. Please let our differences — even within the ASC community — be recognised, applauded and celebrated, not penalised, judged, discredited or disregarded.

With love from **Eleanor**

PS. Thank you for your editorial on page 3 of *AU*. "I am always trying to think of the ways people will misunderstand my choices in putting a magazine together". I found this very good to



## letters in response to Richard (continued) and a notice

hear (although it must of course be very difficult)! I am always trying to think of the ways people will misunderstand me in general! If I write or say anything, I immediately hear a plethora of protests against what I have just said or written, criticisms and differing perspectives. I think this is because I cannot imagine another perspective from my own and my subconscious tries to overcompensate by imagining every alternative. This is usually a bad thing. But how to stop it without causing offence? That is why I do not want Richard to feel criticised by my words; it is so difficult to see another's perspective and you should not have to try all the time, you should just be able to speak or write without causing anger in anyone else, even if you have not been able to think of all the possible different perspectives. Then other people should be able to put their perspective which might be different from what you just said because you could not possibly know what they were thinking.

Even now, as I was writing this email, I was desperately fighting a false image of myself as selfish, trying to advocate selfishly for "people like me" as opposed to "people like you". I know really this is just a negative, critical projection (a misinterpretation of my intentions and words) but it is one which I

often feel if I try to speak up for myself or others with love: I worry that I will be misinterpreted as making a bossy "argument" like a politician might do, and that worry makes me look at how I might be interpreted negatively and wrongly. This in turn makes me project the misinterpreted view of myself onto what I am saying, which causes very bad anxiety and hurt because I am speaking in the only way I can do comfortably and empathetically, even if I am inadvertently treading on someone's toes (or feelings). I thought *It was just an honest mistake* . . . was a great name for Richard's article because that is how I feel almost all the time: like whatever I say will be misinterpreted and criticised because I have not taken into account everyone else's perspective, but it is always just an honest mistake and was really well-meant!

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 are ideas for new themes, and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

**Dear Editor,**

I am writing in response to Richard (Edition 87).

I am the proud mum of a 14-year-old son with autism and have just had the privilege of working with a significant number of young adults with autism and Asperger's with differing levels of function. I just wanted to say that I enjoyed reading his article and wholeheartedly agree with his opinions. For many years I have read research papers that concentrate solely on the deficits associated with autism and in particular refer to the work of Uta Frith and Simon Baron-Cohen.

As such I have felt complete dismay and disappointment at the portrayal of individuals

with autism or Asperger's as being emotionless unfeeling robots. Instead I would like to see research that focuses on the many positive attributes of those on the spectrum and preferably from different researchers as Baron-Cohen, from my experience, appears to have the monopoly in the field.

I would also like to add that my son and every other person that I have met with autism has empathy, intelligence, honesty, intuition, while having the ability to show kindness, gentleness and a refreshingly unique perspective, that is a joy to behold.

Yours sincerely,

**Maxine**

## another letter in response to Richard and a filler poem

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**Dear Goth,**

I have to take issue with what Richard said about PDA. He says “An individual’s actions described as PDA are common among the ASC population to the point that PDA does not officially exist.” I have Asperger’s, as does my eldest child. My youngest child, however, has PDA. I can tell you without a shadow of a doubt there are significant differences between the PDA sub-type and Asperger’s or HFA, and PDA most definitely exists. PDA is solely anxiety-driven and the anxiety therefore is extreme even by ordinary autistic standards. Rather than me explain it all, there is an explanation of it here which Richard might like to read:

**[pdasociety.org.uk/what-is-PDA/about-pda](http://pdasociety.org.uk/what-is-PDA/about-pda)**

and it clearly explains those differences (which are far greater than the demand avoidance) along with separate diagnostic guidance. But I disagree in the strongest terms with what Richard says about PDA. Richard has an Asperger’s perspective, he is not inside the functioning of someone with PDA to know how it feels or presents. The behavioural management and educational support techniques for PDA children differ from those with typical autism. Typically recommended autism techniques simply do not work with PDA children.

I appreciate what Richard says about functioning and environment, however, the social model of disability far from explains all the disabling features of autism. I do get a bit irritated when people claim autism is a gift and not a disability. I would be the first one to say it can bring great gifts with it, but there are many disabling features of it that are nothing to do with society or necessarily even environment. An everyday environment without extremes

can still bring huge challenges to someone with Asperger’s. And of course don’t forget those down the severe end of the spectrum who will always be completely dependent and unable to manage self-care, work or cope in the world without great support. I don’t like the misnomers of “high-functioning” and “low-functioning” either, but that is because calling someone high-functioning, completely undermines their difficulties, just because they are continent and verbal with a reasonable IQ. There are many other ways someone can be completely disabled by their autistic traits. There is someone on Facebook called Bill Nason who explains this really well.

Contrary to Richard, I do not find it insulting to be termed as disabled. I struggle with many aspects of normal everyday life that NTs do not. What I do manage, comes at great cost of exhaustion and periods of Aspie burnout and makes me feel I have compromised my true self. Don’t forget the oft-quoted phrase: “When you’ve met one person with autism, you’ve met one person with autism”, and Richard seems to have fallen into the trap of believing everyone on the spectrum has the same experience as himself.

As for autism genes, autism is heritable but not entirely genetic. It is for the most part epigenetic, which means there is an environmental trigger, which a subset of the population are more susceptible to. So whilst I agree there is too much energy and money being invested into looking for autism genes, it’s not for the same reasons Richard believes this.

There were things Richard said that I did agree with, but I couldn’t let the ones I didn’t agree with go unreplied to.

**Planet Autism**

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If I could hold you in my arms, they wouldn’t be weapons to hold you down.

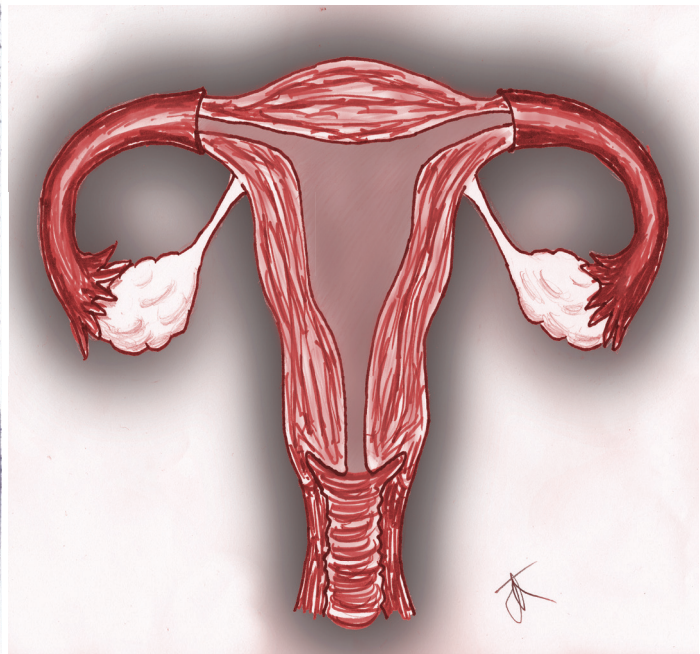
by **Daniel**

## Lookalike



A uterus

(original drawing by Matthew Price,  
the cover of issue 86)



An alien

(drawn by the Lincoln Imp)

Sir,

I am surely not alone in recognising a striking resemblance between the cover of *AU* 86 and a uterus?

Shurely shome mishtake?

**The Lincoln Imp**

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**In April I took my theory test and got:**

49 out 50 on the multiple choice questions and 59  
out of 75 on the hazard perception.

The pass marks are 43 and 44 respectively.

I thought I did quite well!

I passed my practical driving test in an  
automatic with only six minor faults. I learnt with  
a very patient driving instructor.

Before I started taking driving lessons I only  
knew of one other person on the spectrum who  
had passed their driving test.

It would be interesting to know, how many  
fellow readers have taken lessons or passed their  
tests or have considered it?

When I get my own car I will be continuing  
with lessons concentrating on motorway driving.

**Ollly**

## Is Asperger's the next stage of human evolution?

by Nathaniel

For far too long the Asperger's brain has been considered as deficient and somehow lesser than that of neurotypicals (NTs) by both NTs themselves and experts in autism-spectrum condition (ASC). NTs describe ASC as a disability, which is insulting, as it assumes we are incapable of doing certain things. In reality it is a person's environment which makes them disabled and to call Asperger's a disability is patronising and insulting. Why should we be termed disabled just because we think differently? It is no different to terming someone disabled because of their age, gender, race or religion, a practice which is illegal across much of the Western World. Academics have suggested ASC individuals are emotionally inferior in that they lack empathy or, worse, do not have emotions. These attitudes only serve to further ostracise us from the neurotypical majority and undermine the work being done to combat such attitudes.

What if, instead of inferior, the Asperger's brain is actually more advanced?

When we look back to the original work of Hans Asperger, he would agree with this assessment. He believed that "for success in science or art, a dash of autism is essential." Diane Kennedy, author and advocate for Asperger syndrome (AS), has written in agreement with Asperger that Asperger's individuals "are our visionaries, scientists, diplomats, inventors, chefs, artists, writers and musicians. They are the original thinkers and a driving force in our culture."

This can be seen by the many great thinkers of our species who have showed traits of Asperger's. These figures include: Michelangelo, who had a single-minded work routine, unusual lifestyle, limited interests, poor social skills and various issues of life control. Norm Ledgin, author of *Diagnosing Jefferson*, indicates that

Thomas Jefferson, author of the American declaration of independence, was shy, had an inability to relate to others, had difficulties in public speaking and was sensitive to loud noises. He also had an obsession for remodelling his home and was very eccentric, all of which are symptoms of high-functioning autism and AS. Prof. Michael Fitzgerald stated that Darwin was a solitary child, and even as he grew to be an adult, avoided interaction with people as much as he could. He wrote letters often, but did not often partake in face-to-face communication. Darwin also collected many things and was intrigued by chemistry and gadgets. This fixation on certain topics is another characteristic often seen in autistic people. Fitzgerald describes Darwin as, "a rather obsessive-compulsive and ritualistic man". Together, these characteristics point to the conclusion that Darwin had some form of autism. Sir Isaac Newton was very quiet and not good at small talk, or typical day-to-day conversations. He was extraordinarily focused on his work and had a hard time breaking away. He was often so focused that he forgot to eat. Newton was not good at keeping or making friends, nor did he know how to talk with individuals he did consider to be friends. He also relied strongly upon routines. For example, if he had been scheduled to give a lecture, that lecture was going to happen whether there was an audience or not.

Is it an advantage to have AS? Is it an insurmountable burden? Or is it a difficult balancing act between both extremes?

Asperger's is not a curse we shoulder and have to hide from others, but rather the next stage of human evolution which we have been blessed with and should revel in. Dr Temple Grandin is one such individual who believes that her disorder is an asset. She called NASA a sheltered workshop for people with Asperger's and believes that people with ASC are the great innovators of



## an article (continued), a letter and a filler

our civilisation. She said that “if the world was left to you socialites [NTs], nothing would get done and we would still be in caves talking to each other.”

Many people who are experts in Asperger's write about the positive aspects of Asperger's. Deirdre Lovecky notes how individuals with Asperger's often have advanced vocabularies, recognise patterns others do not, and pursue ideas despite evidence to the contrary because they are not easily swayed by others' opinions. Their ability to focus on details means they can come up with solutions to problems others overlook. Asperger's individuals are also often willing to spend long hours in laboratories and in front of computer screens or buried in books because they do not mind being alone. All this enables them to make tremendous contributions to humanity.

Beyond the intellectual, author Patricia Bashe points out that people often admire those who can work independently. She writes, “Our society celebrates the individual who does what he thinks is right and goes his own way.” Because of their unusual reactions to stimuli such as light and sound, Asperger individuals see the world differently than most people. They comprehend multiple levels of meanings of words and can be fabulous punsters. Asperger's individuals can make amazingly loyal friends. They do not manipulate people but speak out frankly and honestly. They are sincere truth-tellers, whose trusting nature makes them incapable of backstabbing. As employees, they are completely dependable. Psychologist Teresa Bolick writes, “their deficits are actually assets, as they are unfettered by convention . . . Aspies help us stay grounded by questioning why we do what we do” and basic societal assumptions.

Parents who have successfully raised happy and productive children with AS often advise others to never give up or become discouraged. An Asperger's individual who receives the right help and professional services can lead a happy life which can also further our species more than a NT brain could ever comprehend. So if you ever feel disheartened with the world remember that you are in the company of some of the greatest minds the world has ever seen and are a vital cog in the global machine, without which the world would be a poorer place.

**Dear Goth,**

a recent issue has disclosed Aspie traits, in various correspondents. James Christie, pointing out our creative rebellion; John, pointing out the meaningless, bland chit-chat that we avoid (my mother always said that I would only open my mouth if I had something important to say); Rachel's point about noise — we are library people, not noisy sporty types — struck a chord in that thought requires silence and stillness to concentrate, as noise disperses attention — that is the science of mind behind this.

People think we have no empathy because we don't get caught up in emotional outbursts. The truth is that we use our minds to find solutions, not our mouths to protest the unfairness of life or to shout support for one course of action over another. We are reasonable beings, not emotional ones. We don't gesture or cry out inane. Our brain waves show we are present — not buried in the past or rushing headlong into the future. We face reality as it is — not as it was and we want it to be again, or we want it to be in the future — therefore there is no emotional content in our lives as motion and emotion are synonymous. We are going nowhere but here, facing nothing but now and there is no motion or emotion in that.

**Tony**

PS. Another point that John raised is our need for precision in what we say — hence rehearsal and writing out our thoughts, rather than blurting out whatever comes into our heads as NTs seem to do.

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Deep in the soul, below pain, below all the distractions of life, is a silence vast and grand — an infinite ocean of calm, which nothing can disturb: nature's own exceeding peace, which surpasses logical understanding . . .

**by Tracey**

## Letter to my younger self

from Lydia

**Dear younger self,**

oh, I can see you clearly now (and that's not a Bob Marley lyric!). The somewhat scared little girl, bewildered by the outside world. You know something? That's okay. We had good, tough years, without a diagnosis: being mercilessly teased for crocheting and falling off the bus, daring to be passionate, and wanting to leave the cage of your classmates.

You were two months shy of sixteen when the diagnosis came. How many years waiting? How many tests? You could have said it all along.

It's a lesson to learn: you will feel different, become frustrated, angered even. The world is neurotypical. You're not. Understanding is not a priority. But I would not have changed a thing. Because it came with skills you'd have otherwise lacked. Now I see how limiting those years were.

Caged, caught in the gap, curious about the world; it was different to that of your peers, who were still gabbling with being younger than their years. The "adult" jokes were not funny, yet they laughed; you were told you were too serious when a boy ran in the girls' toilets. (That still isn't.) Yet without those years, you'd never have achieved what you have so far. Columnist? Blogger? Interviewer? Nobody would have guessed. Not a single one. Not even you.

Aspergians are special — and that's not meant arrogantly. Every Aspie you'll meet will impact you in so many ways — the girl who's your best friend, "the one that got away", and many more. Little professors to the core. They make the world you are, and tentatively explore a better place. It's huge. And worth exploring.

You're made of words, almost — a condition that defines medical words, of books, and lyrics. I see a wish you're nurturing — for no Aspergian to change. Not one.

They are the best of the best — eccentrically cool, unafraid, and knowledgable. Yes, the girl with famously defective vision, wonky teeth, and a bad fringe: I see you. I won't ever forget you. Aspergians are special beyond compare. You'll learn it soon. And anyone reading this should know that also.

Good luck,

**Your future self**

X



## 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.
- 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 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.

## Small article about the *Neurodiversity Manifesto*

by Joseph

In May 2016, an autistic activist, Monique Craine wrote an open letter to Jeremy Corbyn and John McDonnell. She expressed her disappointment about the lack of representation and obstacles that face neurodivergent people (autistic, dyslexic, dyspraxic, ADHD and so on). She has also called for a shadow minister for neurodiversity to be appointed.

To her pleasant surprise, McDonnell and Corbyn took these ideas seriously. John McDonnell requested Monique and another Autistic activist, Janine Booth, to form a steering committee to write a Neurodiversity Manifesto. The steering committee wants this manifesto to be broad-based and inclusive and to reflect the opinions of as many neurodivergent people and labour movement activists as possible. If all goes well, this manifesto should influence Labour Party policy towards neurodivergent people.

Our main points are listed on the right, but the final content of the manifesto will be a distillation of what neurodivergent people want, so please feel free to add to, or take away from these:

- Diagnostic/identification service available to all
- Stop and reverse cuts; expand services
- Education and training about neurodiversity at all levels, for political decision-makers, teachers, employers, administrators of justice, education staff, public-service providers, (prospective) parents, and so on
- Replace Work Capability Assessments with Workplace Accessibility Assessments
- Apply the principle of universal design to make the built environment less distressing and more accessible
- A strategy to tackle bullying and hate crime
- “Neurological status/condition/divergence” to be an additional protected characteristic under the Equality Act.

If you are interested in taking part in this consultation please send an e-mail to **neurodiversitymanifesto@gmail.com** or write a letter to *Asperger United*, who will forward it to us.

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*Asperger United*, c/o The National Autistic Society, 393 City Road, London EC1V 1NG  
Telephone: **0808 800 1050** (free from most landlines) or  
Telephone: **020 7923 5779** (geographical charges apply)  
Email: **asp.utd@nas.org.uk**  
Website: **www.autism.org.uk/aspergerunited**



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