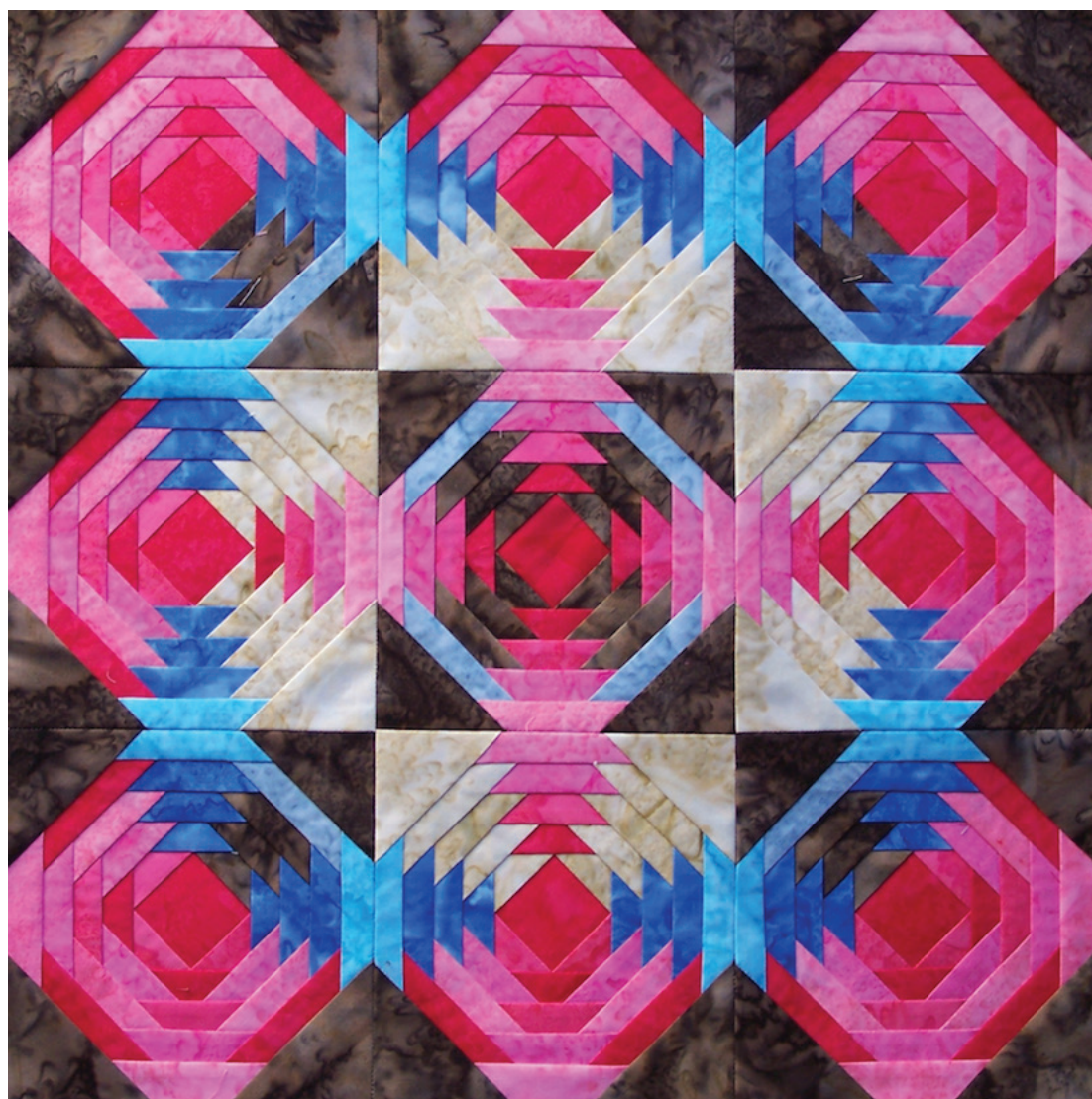


Produced by and for people who have autism-spectrum conditions

# Asperger *United*

Edition **82** April 2015

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# Asperger United

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

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

*Asperger United* is free. To subscribe you, we need your postal address. We ask for a contribution of £9 per year from overseas readers and £15 from professionals and institutions to cover postage costs. Please make cheques payable to the NAS. Organisations requiring multiple copies: no extra fee, please get in touch.

**Editor:** the Goth

**National Autistic Society production support:** the Publications Team

**NAS phone support:** the Supporter Care Team

*Asperger United* was founded in 1993 by Pamela Yates and Patricia Howlin, in association with the Maudsley Hospital, and Mark Bebbington and Judy Lynch of the National Autistic Society.

This was in response to a recognised dearth of services for people with Asperger syndrome and the potential for self help and networking as a means of support for this group.

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds, John Joyce and the current editor, the Goth (who does not wear black).

Pamela Yates provided support and advice to the editors until the publication was handed over to the National Autistic Society in 2000.

The name *Asperger United* was chosen by the group of original readers as the most "appropriate name" for the publication. This was suggested by Anna Kaczynski, formerly Cohen.

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

*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)  
Fax: 020 7833 9666

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

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

Thank you to Graeme Lawson for producing the *AU* logo.

Please note that the views expressed in *Asperger United* are not necessarily those of the editor, the National Autistic Society or those involved in the publication of the 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 postal or email address above.

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Contributions for the next issue should reach *AU* by **18 May 2015**

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

To avoid waste, I am thinking of asking you to confirm you still want to be a subscriber, and to ask you every three years. This will save me sending the magazine to people who do not read it any more.

To keep the amount of work manageable, this scheme would be introduced gradually over the next few years, and you would receive a form with instructions along with your magazine. All you would have to do is go on line if you can (this will save me a lot of work) or fill the paper form in and send it back to me. Then I would record that you were confirmed for three years.

Please let me know how you feel about this plan. I want to emphasise that it is not starting now, it is only a plan, and you would have more than one opportunity to confirm your subscription, so please don't worry about missing the form. I will make every effort to make this as stress-free as I can.

Lastly, the theme *late diagnosis* seems to have really struck a chord, even though you could have written in with the same letters and articles under the diagnosis theme, that extra word has made a huge difference! It was a bumper postbag.

As ever, I look forward to your letters,

**the Editor**

## the late diagnosis edition — the next-issue notice is on page 9

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## Late diagnosis

by Lynne

After having experienced difficulties for the first twelve years of my marriage, it was somewhat of a shock to have our counsellor diagnose me with Asperger's at our first counselling session, counselling being a last ditch attempt to solve our problems before splitting up. I was 35 years old.

For the first year after “unofficial” diagnosis (our counsellor didn't have the right letters after his name to “officially” diagnose me), I was in denial — I couldn't be autistic, oh no, not me! And life felt like walking through a minefield, with all these “bombs” waiting to go off when I hit them — the “bombs” being situations that I would certainly experience in the near future — but I was slowly seeing that when I got to the “bombs”, I never knew what to do with them and they would blow up in my face. Before diagnosis I never thought about situations that had never occurred before and what I would do if or when they happened; now I was worrying constantly about what could happen if I did this or said that and I ended up over-analysing everything.

My long-suffering husband helped me through the first

(bad) year and learnt how to talk to me so I could actually understand what he was saying (which resolved 99% of our marital problems!) so eventually I accepted my AS status and then promptly tried to forget about it. The next two years were spent no longer in denial, but in acceptance and forgetfulness — AS didn't really affect my life, so I didn't need to worry about it and I certainly didn't need to bother with an official diagnosis.

Then my husband suffered a life-changing illness and we both realised that money wasn't everything and being happy should be the main priority. I started to think that maybe it would be better to be officially diagnosed and then I could tackle my own happiness at work issues (by this time, I had been a manager in my organisation for seven years and the stress of managing three members of staff just seemed to be getting worse and worse: it never got better and it constantly affected my life at home, causing sleepless nights and fruitless conversations with hubby).

So in 2014 I referred myself to the NHS for a diagnosis. It took eight months to get an appointment and hubby came

with me, whereupon the good doc quizzed both of us for two hours before confirming the diagnosis of ASD (Asperger's). He advised me to “stop trying to be the best normal person that you can and be the best autistic person you can be”. And told me to get a job where I didn't have to manage people.

At 39 years of age, with my official diagnosis, I finally felt that I knew who I was, what I was and why I am the way I am. A week after diagnosis I met with my HR lady and told her. At that time she knew nothing of ASD and only a little about Asperger's but was so good with me that I wish I had been diagnosed (and told her!) a lot earlier! Initially, she supported me by being there for a chat if I had a situation at work and didn't know what to do (previously I would have gone home and asked my husband for his advice or tried to deal with it myself, the latter inevitably ending up badly).

As that had gone well, I decided I should also tell my netball club (I have been playing netball for six years and became a C-award umpire eighteen months ago — netball rules are very clear and there are no grey areas, so this suits



me very well as an AS person). Previously I always ended up leaving the clubs I played for, mostly because people got annoyed with me saying the wrong thing, or being very uncoordinated from time to time. This was my fourth club and when I told the captains of the two teams, it turned out one of them (who I knew was a teacher) taught children with autism so probably knew more about it than me! They quietly told the rest of the ladies and I have noticed an adjustment in people's attitudes towards me even though none of them have asked me about my AS yet — they definitely accept me for me now and are more relaxed with me.

At the beginning of this year, after another run-in with a member of my staff left me in tears and leaving the office late on Christmas Eve, I decided enough was enough and, with HR's support, plucked up the courage to tell my bosses about my diagnosis and to ask them if, with the current re-structure of the department, due to two staff members leaving, they could re-structure my role as well and remove my staff management responsibilities. A month later I have been "staff-less" and pretty stress-free for the last two weeks! I think it helped that my bosses thought a lot of my work and of me but if I had remained a manager of staff, I would have left and found another job with no such responsibilities. Luckily, it hasn't come to that.

I know I am one of the lucky ones — I have never been willingly out of work (touch wood) and have a one-in-a-million husband who loves me unconditionally (even when I drove him mad when he thought I wouldn't change me or what I did because of stubbornness — we'd never heard of AS before counselling). I also have a few close friends who accepted me no matter what and because they appreciated my good points, just accepted the bad points as "Lynne just being Lynne".

Before being diagnosed, I told very few people as I was worried that they wouldn't necessarily believe me (my brother-in-law was a disbeliever and knew me quite well), despite one friend telling me:

"Anyone you told would be honoured that you told them, everyone else, I wouldn't worry about, if I am honest."

She was right but the official diagnosis meant I could follow her advice without worrying quite as much.

I would encourage anyone to get a diagnosis, no matter their age or where they are in life. It has helped me immensely to accept me for me, to love me for being me and to find the best way to happiness and not to try and fit myself into a "normal" world when I am not normal, I am Autistic Me !!

## Group notice

### Dear fellow people on the spectrum,

I would like to hear from you if you would like to begin an Autism Rights group in the Bristol and Avon area.

Together we can be a stronger voice for our needs and campaign for our rights.

You may be wondering what this has to do with you?

If you aren't able to get the support you need, suitable housing or medical treatment or just feel excluded in some way we can support each other to demand that the society makes at least reasonable adjustments so we can live within it without our autism being a disability and preventing us from living out our lives. If you live in the Bristol area and identify as being on the spectrum I would like to hear your views on this.

You may be wondering why when we have the NAS, the autism forum and BASS would we need anything else?

Well do you feel that you are really consulted, your views acted upon and your needs met?

I look forward to receiving your views on this.

James

## Being an unperson

by Richard

Being an unperson is being treated as unable to make decisions. Unable to have opinions. Unable to want things.

Being an unperson is having people try to fix you. Having people try to make you human and whole.

Being an unperson is having people talk to a stereotype instead of you. It's having people talk to your autism, or your depression or your sad feelings instead of you.

Being an unperson is people being convinced you have no internal motivation, and they must construct it for you, out of gummy bears and M'n'Ms.

Being an unperson is being treated as a problem to be fixed, behaviours to be modified, someone else's woeful burden, someone else's grand accomplishment.

Being an unperson is saying, "I feel like this" and being told that no, you don't.

Being an unperson is having someone look at you. Or having everyone stare at you as if you can't see them.

Being an unperson is when people treat you life as a horror movie. When they say, "imagine being this person" to make people cry and give them money.

Being an unperson is when you must learn to take perspective but you don't have a perspective to take. When you must learn not to make others uncomfortable and to expand your comfort zone. When you are hurting people's feelings by acting like you have feelings to hurt.

Being an unperson is having people ask the person next to you what you want to do.

Being an unperson is telling people about this, and instead of saying, "That's awful. We should change that," people say, "I never saw that happen." People say, "No one saw that happen." (It doesn't count that you saw it happen: you are not a person.)



Being reflective by Tammy

# Pen pals

## Pen pal number 192

**Hi my name is Tracey**, I'm 20 years old and I currently live in Crewe. I was diagnosed with dyspraxia at the age of 15 and I was then diagnosed with autism and Asperger's at the age of 18.

I used to go gymnastics and I was part of special Olympics Great Britain. I have represented Great Britain three times and I have even beaten the USA. I have now retired after doing gymnastics for 16 years but I'm now looking for a new hobby.

I have many hobbies like watching *The sound of music*, skateboarding, rollerskating and cooking, but my favourite hobby is reading joke books.

I would like to be connected to someone through pen pals who have similar issues and interests as me and I would like to speak to a female person as I find it easier to speak to females.

I hope you like reading my advert and hope to hear from you soon.

## Pen pal number 193

**Hello my name is Andy**, I am 20 years old and live in Birmingham. I am a proud Aspie after being diagnosed at the age of 7. My interests include tennis, snooker, playing the piano and also playing Playstation games. I also like listening to music as well as doing art and I like going walking. I would like to hear from someone with the same interests as me.

## How to place a pen-pal advert

- All you need to do is send your advert along with your name and address (and email address if you want) to *Asperger United*. You can use the Royal Mail or email. The next pen-pal number will be given to your advert when it arrives.
- Please note that *AU* does not print dating adverts, as it is unable to provide suitable support.
- Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.

## How to reply to pen pals

- Please remember to let us know the name and number of the person whom your letter is for. (All pen pals are numbered by the editor, not the person who sends in the advert.)
- Please remember to put your address on your letter.
- To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London, EC1V 1NG, or email [asp.utd@nas.org.uk](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.



## Pen pal number 194

**Hi, my name is Samantha** and I am 21 years old. I was diagnosed with Asperger's three years ago and although I now work and can drive, I feel that I am still struggling daily with my social life.

I like writing, reading, walking my dogs, listening to music, shopping and surfing the Internet. I also love animals and as well as my four dogs, I have a cat.

I live in Bedfordshire and although I would like to hear from people around my age in my area, I am happy to hear from others too.

## Pen pal number 195

**Hi, my name is Shane.** I live in York and I am 33 years old. I was diagnosed with Asperger's in 2009.

I like all kinds of shipping areas and I like construction sites and watching the piling rigs at work.

I would like pen pals who have similar interests to me. I enjoy talking about piling, civil engineering, telecommunications, politics, films, dancing, demolition, history and construction.

I enjoy watching films and television and love old films in particular. I take part in jive classes and like watching construction sites. I am very knowledgeable about sites of all kinds. I am very passionate about my interests and hope to find someone to write to with a similar passion.

I am originally from York and have some friends here but I am always looking for more.

I look forward to hearing from you.

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

## Pen pal number 196

**Hello all, I hope you are well,**

my name is **Atikea**, I'm 43 years old from the North-West of England, I live with my wife and four children.

I was diagnosed with Asperger's four years ago, and always try to learn to apply myself to live independently and cooperatively.

I have been a active reader of *Asperger United* for the past two years, and would like to be listed and allocated a pen pal number.

I hope to make friends with the people who have interests in common with mine.

I enjoy reading English literature, poems in both English and Arabic, writing and translating between both languages.

I am learning web development skills, with computer programming, and would like to talk to others who have an interest in IT: html, css, javascript, jquery, php, mysql.

I also enjoy jogging, sprinting, learning new skills, like electronics, leadership skills, freelancing, humourous studies, psychology.

I look forward to hearing from people of a similar age and interests.

## Pen pal number 197

**My name is William**, I am 17 years old. I have Asperger's, and I am looking for a friend. My hobbies are going swimming and the gym, going to the cinema to watch new movies, KFC, and meeting new people, and my dislikes are: I have no dislikes! I don't hate anything. I am friendly and kind.



## Autism and creativity

by **Michael Fitzgerald**

Routledge

ISBN: 978 0 41576 342 4

£30

review by **Elkie**

Although the author bases his argument on the assumption that autism is a predominantly male feature and therefore only explores the life of famous men, he presents in a highly readable and credible way the relationship between autism and creative achievement in areas such as invention, philosophy, politics and writing. Analysing the biographies of men like Ludwig Wittgenstein, Eamon de Valera and Lewis Carroll, Professor Fitzgerald teases out the autistic traits underlying their unique ways of thinking. Thus the book puts autism in a new, positive light, as lack of social restraints, fixation on detail and a desire for perfection are in fact prerequisites of genius and necessary to advance humanity.

It makes the case for the autistic mind as potentially uniquely creative and not, as often portrayed, defective and inferior. A book for scholars and lay-people alike, which will leave you full of hope and awe.

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

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

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

Dear Goth,

I am writing in to *Asperger United* because as an Aspie who has struggled socially I would like to encourage other Asperger-orientated people.

Personally my view of the condition is that it does in reality affect us socially and result in social struggles. But that does not have to be the end of the story.

The work of *Asperger United* over past years has been fantastic in helping people like myself.

I've read a lot of encouraging articles. So my view is that we can all try. And we can all learn.

We can learn both social skills and how to accept ourselves. If one learns to take pride in what they do, the world opens up. We can let others into our world, and then we can be happy and successful!

**Thomas**

**TIME TRAVELLERS  
WON'T TAKE NOW  
FOR AN ANSWER**



If sufficient material is sent in, the theme for July will be **women**. I don't just want contributions from women. Any contribution that features women or a particular woman fits the theme. 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, fillers (for putting in small spaces like this) and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

## letters to the Editor

Hello,

I've just come across *Asperger United* magazine on line for the first time, and found it interesting. But I noticed there are hardly any women as contributors. I wondered whether this was usual, and perhaps it reflects that men are more likely than women to send contributions. Perhaps *Women with Asperger syndrome* could be a theme. It could prove interesting, as the syndrome presents differently in women and it would be nice for women in particular to read about one another's experiences!

Best wishes,

Amy

*Women are about 20% of the readers, and 25% of the contributors to last issue, which was unusually low, you are right, Editor.*

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Dear Editor,

thank you for the latest edition of *Asperger United*. To be honest, the articles about *Dr Who?*, Tardis and *Da-lek* made me feel more alienated from the readership than ever. As I do not watch tv or read science-fiction books, but prefer to spend as much time as possible in the natural world, I have no clue what these people are talking about.

You were wondering why "fandom" proved to be such an unpopular topic. What exactly is fandom? It's not in the dictionary and nobody around me has heard of it either (unless you mean fantom?). Maybe it's one of those new computer words that are being invented on a daily basis, making it harder and harder for people with language or communication disorders to understand what is being said or written.

Instead of the many personal (problem) stories, I would like to see more general, research-based articles in the magazine, but perhaps I'm in the minority here.

Elkie

*"Fandom" is the other side of stardom, originally referring to all the members of fan clubs (for example, "the Star trek fandom"), and now used more generally of fans, especially if they attend fan events, such as conventions, Editor.*

Dear AU

I enjoyed the Doctor Who? special! It was good reading Laura's article and the story about Peter Capaldi, Jenna Coleman and the little girl with autism very nearly made me cry. What lovely people they are, and what a lucky little girl! I've watched (and loved) all the episodes since the relaunch, but only fairly recently have I started watching from the very beginning. I'm onto the second Doctor (Patrick Troughton) now, but William Hartnell as the first Doctor was amazing. A bit like watching your own, rather eccentric, grandfather travelling through time. Plus, you have to love the fluffed lines, wobbly sets and man-in-a-costume aliens! So far Matt Smith and Karen Gillan are my favourite pairing: the Amy Pond storyline was brilliant. I miss her so much!

In her article Kim was wondering why the Doctor is so popular with Aspies. I wonder if it's because he's an alien, when he visits Earth he doesn't really understand humans and their emotions, the human companion is always there to provide the emotion in the stories. I think us Aspies probably relate to him feeling like a stranger amongst people, in his case a literal alien.

On a different note, I read the plea from Tim about the Asperger support group in Essex. I've always found the idea of an Asperger social event to be a bit of an oxymoron. Maybe you can't get your members to attend social events because they have a social disability and wouldn't enjoy social events, I know that I personally avoid them like the plague! Maybe you could send out an email or letter to all of your members asking if there any activities they would like to do, maybe in smaller groups? I hope you can get some sort of advice from **other readers**.

Cathy

## a letter to the Editor, a letter, and a poem

**Dear Editor** and readers,

following the Goth's book review and submissions invitation related to late diagnosis: there is a group for whom diagnosis could only ever come late, given that the Asperger's diagnosis didn't become a UK option until the 1980s, by which time they were already in the psychiatric "system".

Whilst Philip Wylie's book does address risks of misdiagnosis, it seems rather cagy about details and statistics. This doesn't help people whose late diagnosis is viewed as being superimposed on longstanding co-morbid diagnoses that may have seemed inappropriate or extremely ill-fitting to them and those close to them. Worse still, there is a distinct possibility that longstanding treatments, against the diagnosis rather than

the problems being experienced, may have complicated things or even made them worse.

We've often noticed that subtle use of medication has been useful, whereas increased dosage has only raised levels of distress and anxiety because often the first effect is reduced capacity to self-control.

In the late Sixties my wife was advised by a psychologist to stay away from psychiatrists: I really wish she had, but the developing range of medications offered help with anxiety and periodic depression and each doctor believed that their favoured remedies were the best option, if you didn't look too closely at how subjective their **opinions were**,

**Dave**

**Hello all AU readers,**

I was in my late fifties when I was diagnosed with Asperger's syndrome. My perception is that the lateness of the diagnosis was a blessing. I was at an age where I could stand up for myself. Conformity to social norms is contrary to my nature. My nature is not to have the common human desire for human company.

I do wonder how I would be now if I had been diagnosed when I was a child? I have seen documentaries where "experts in autism" seem to think that all humans are or *must* become social beings. If such thinking is absolute then such thinking is wrong. I suspect that such a way of thinking would have been injurious to my mental health. As it is, I have never had any mental health problems.

**Michael**

Do You Still Love Me?  
You are my angel;  
The sweat smell of hazel.  
You mean everything to me;  
We live in harmony.  
The Earth is blue;  
Do you still love me?  
Because I love you.  
Dove is love;  
Love is dove.  
See the roses;  
Our love never closes.  
Your curly hair  
Will always be there.  
It's a piece of art;  
Your love is in my heart.  
My love isn't only in your mind;  
I'll be forever kind.  
Love has nothing to do with money;  
You are my dearest honey.  
So we should know,  
Let our love grow.  
You are for me very Heavenly.  
That's the way we have it;  
Our love is marvellously magic.

by **Tomislav**

## A late diagnosis in my late fifties

by Pamela

I had no clue what Asperger's was until the late 2000s. I'm born and raised on a small-holding in a tiny village in the American Mid-West in the 1950s. My father died in a construction accident when I was young; mother remarried and I eventually counted seven brothers and two sisters as siblings. I came to the UK as a bride around 2000 after a long Internet relationship, marrying who I was later to discover was another Aspie. All we knew then was we had a tremendous amount in common. Our marriage has worked very well for a number of years now.

I first heard about Asperger's in a curious case of someone who had gotten into trouble and was insisting he not be held responsible for his actions not because he was insane, but because he had a learning disability. He certainly seemed very intelligent to me: his actions indicated he had high intelligence as well as extraordinary computer abilities. I set out to learn more about this "Asperger's", reading whatever I could but not finding much dealing with adults. This was perplexing, as it was said to be lifelong but everything written dealt only with children.

and it really did seem a lot like me. We found an Asperger's tests on line and I took it — no problems. My husband stood behind me looking at the computer for quite a while before asking me to print off the test without my answers. We sat at the dining table going through the test, discussing each answer exhaustively. My version of the answer was almost diametrically opposed to his version of what I finally realized was the truth.

It took a long time, but finally dim memories came to the surface of my mother "teaching" me how to "correctly" answer personnel and personality questions and these types of tests, carefully explaining how I wasn't lying but simply giving the "right" answer. Giving the "right" answer on those forms was like giving the right

answer on tests at school, right? I memorized the "right" answers just as I memorized the "right" responses my eldest sister gave me to basic social questions and situations. That's how everyone learned these things, right? After all, that's how I had learned them. Still, now that I think back, I don't remember my siblings learning things that way. And I have an excellent memory.

Unfortunately I had gotten so good at giving the "right" answers to all those tests that I actually believed they were the correct answers to how I felt and acted. The truth was, I was clueless. What was obvious to everyone else was a total mystery to me. Some of my husband's answers to how I acted or felt were, quite frankly, completely shocking, but after I'd slept on it I had to admit he was correct. My final score went from "no" to quite a bit higher than "autism likely".

My GP did a small test in his office (where I tried hard to answer truthfully and not just give the "right" answer) and was referred immediately for testing. The home visit was the very hardest for me. I don't feel comfortable with strangers and rarely have them in my home and suddenly I had not one but two strangers come to my home for a long solo chat with me and some testing. I was quite determined to find out the truth by this time, because suddenly remembering that what I believed myself to be had been taught to me (in fact, drilled into me) meant my internal life was feeling quite chaotic. I was in my late fifties and I suddenly no longer knew who or what I was. Nearly a year later, after months of interviews and tests, the written diagnosis arrived in the post. That was two years ago.

As my mother doesn't live in this country, is quite elderly and has aphasia, she wasn't able to be interviewed to give details about my early childhood. I gave answers regarding myself as a baby and toddler as I remembered being told by



my mother and older siblings. I made calls back home for information, relaying their answers. During the final interview, the psychologist met my husband for about thirty minutes, after which we were told he was presenting with “classic asperger’s”. The clinic wanted to immediately book him in for formal diagnosis but he declined, as he felt it would affect his position at work.

Without direct information from my parents about any speech delay, my formal diagnosis is “autistic spectrum disorder”, unable to clarify if it is Asperger’s syndrome or high-functioning autism. It’s easiest to say “Asperger’s”.

As I had called siblings looking for information on my childhood, I had been asked to let them know the results of my diagnosis. My family has always been close and I was happy to tell them, so I started making calls back home. I was prepared for surprise and maybe a bit of dismay, but nothing too serious. I was not prepared for what happened.

I called my mother first: even with aphasia she managed to tell me she had known I was autistic since I was small, but had never told me. She had no explanation for not telling me and ended the call. My siblings all had the same response: anger, followed by ordering me to call the clinic and inform them that “[I’d] had a lot of fun” but “[I] wasn’t autistic”, I was “a psychopath”. And that’s what the diagnosis should read: “psychopath”. (And then ordering me to find a job, never minding that I am a housewife.)

My family wasn’t interested in my diagnosis because they’d decided what they wanted it to be. To admit I was autistic meant that all the mean things they did and said to me all these years for things they thought I was doing deliberately were wrong because I had a learning disability. They were wrong. And they don’t seem willing to accept that or to say they’re sorry.

Outside of some nasty text messages from one sister threatening me if I didn’t do as she wished, none of my extended family have been in contact with me since that day. I have been told

my mother’s still living. My only child, who has always held me in contempt for “being eccentric”, is now openly contemptuous and argumentative. And my beautiful granddaughter told me she never wanted contact with me again, without explanation. (The sister sending the nasty text messages was asked, by text, if she felt threatening someone she “knew” to be a psychopath was a smart thing to do . . . silence . . .).

I thought the diagnosis would make things better with my family. I’m told the reaction I’ve received from family members is highly unusual. I was told by the clinic to give them time and after they’d had a chance to think about it, the majority would accept me and my diagnosis. I’m the exception to the rule: my family has not only never tried to reconcile or re-approach me about the matter but continues to state I was actually diagnosed as “psychopathic”, not “autistic” (when they communicate at all) and insist on no contact until I admit the same.

To me, personally, receiving the diagnosis was fabulous. I felt vindicated that no matter what other people insisted, I didn’t do things to be deliberately mean, callous or insensitive. After reading the full diagnosis even I was surprised I had managed to raise a child completely by myself and maintain employment. (Though I will be the first to admit I rarely stayed at any job for more than five years and though I tried hard, was not thought well of at several of them.) I really had been trying hard to make sense of what are essentially the shifting sands of social interaction. No one could say I was unintelligent, but I was tired of being told I didn’t have “common sense” because of what others saw as social faux pas.

I really am different — an alien on an alien planet. My diagnosis has been both a curse and a blessing — but I would say the blessings win. It isn’t all my fault. I am doing the best I can. I am who I am and that really can’t be changed, whether others accept it or not.

*As regular readers know, I seldom comment with opinions, but I feel I have to whole-heartedly support the sentiment that we are not at fault for who we are, Editor.*

## AS adults with parents who have undiagnosed disorders

by Joe

I was diagnosed with Asperger's syndrome when I was 21 years old. I believe that my father also has the condition but this is unconfirmed.

I want this article to reflect how hard it is being a son of a person with a behavioural disorder. All my life my father was never there (I lived with my mum) and it felt like a different world whenever I went to his house. I was so used to life in a particular way that it always threw me a little whenever I came back from him.

My father had a difficult childhood himself and this was compacted when his father hung himself soon after I was born. When he was 17 my father ran away from a psychiatric hospital at which he had been sectioned. This gives you some idea of his suffering. He went on to have five children by various women: I am the last child. He built up a successful business from nothing, becoming a respected businessman in his community. However he never confronted his demons. This in turn affected his children, myself in particular because of my disability.

Here follow three examples of misguided parenting of which I was in receipt. One as a child of seven and two as an adult (I hasten to say there were many more of when I was a child).

In an informal mock-up play my father played the wizard and I was the helper. He had a metal spoon which he hit on his head saying it didn't hurt (he was wearing a colander as a helmet).

He then hit my head really hard (as a sort of comical effect) but in actuality was cruel. This was a memory I had blocked out until I saw it again on film. I was very shocked that this had happened to me. Many other unpleasant events occurred during the years from 7 to 22. Years later I was trying to regain contact with him, and I was pleased when he wanted to come kayaking

with me. My mother was also there as a spectator. However the day was really hot, and I suddenly felt strange in the car.

On reflection I realise that this feeling was coming from a place of fear, as I knew he would criticise my kayaking, and it would not be a joyful experience.

I then told him I was feeling ill, and he said, "I had to re-arrange my morning to come out today". I tried to get away from him, but he tapped me on the shoulder saying "don't you walk away I am not done with you yet". He then went to punch me with his fists, but my mother stood between us. The kayaking group consisted of people with varying disabilities who witnessed this event. This was why my Father was allowed to join, because he had a mental health issue. As it happened, he went on to enjoy his afternoon kayaking; my mother and I watched instead.

Later on I tried to again build bridges. My mother and I went round to his flat for a meal. We were having a cheerful evening; I felt relaxed as it was nice to see my parents interacting as they had never been in the whole of my life. I reached out for a banana, and my father exploded with rage. The reason being that he vehemently objected to my taking a banana without requesting his permission. He spoke to my mother about me as if I wasn't there in a derogatory way after having shouted at me. My mother upped and left: I followed. I have not spoken to him since. Although he has apologised, I have to care for my own mental health and this is the best way forward for me.

Thank you for reading. I have written this article in the hope that other AS sufferers need not feel guilty about how they may have been made to feel by parents who may not have been diagnosed.

Dear AU,

I am sending you a cover image of my patchwork. A block called *The pineapple*, worked here in nine squares, and when each square is assembled the squares create a further pattern with each other. The blocks were foundation-pieced, a type of patchwork, and you either like it or loathe it: so many different patches to get in the right place! I did this from my head, but simpler, smaller patterns can be done also. I love all patchwork, hand and machine, and I've recently done appliqué too on the the sewing machine using specialist papers rather than material, which can be cut into shapes and sewn down decoratively.

Creativity is a part of my mind which is unaffected by life. I get very distressed at what life throws at me, especially my experiences of years ago. I had no diagnosis until the age of 27, and a lot of damage was done before this by unsympathetic staff on mental health wards. Many staff were unsympathetic to my quietness and bullied me relentlessly: I didn't know how to change. I now have a Health Passport stating that I am autistic and it gives information on my condition and abilities, and it says how to care for me and what makes me happy and what makes me sad.

I've been creative all my life, doing all arts and crafts, especially drawing, knitting and sewing. And now, especially, designing takes up my interests and I write and publish my own knitting patterns: it's simply bliss to have a job that is your favourite hobby too. I took the step of becoming self-employed two years ago with a design business and I find I have plenty of work — not enough time in the day to do it all.

I like to encourage other people to get busy creatively. I'm helping a carer knit her first knitted item — a beret — great fun we're having! Fifty stitches she's cast on and she needs ninety-one, then I just have to nudge her in the right direction to do the ribbing. I find creativity therapeutic and most enjoyable; I don't know where I'd be without it,

Sarah

## Late diagnosis

by Mary

A family friend read an article about Asperger's. The more she read the more she thought "That's John". So she showed it to John's wife, who agreed. They puzzled about how to present it to him and eventually the wife just pushed in front of him and said "Read that". As he read it he also realised he was reading about himself.

The next step was the GP. The GP said "What's the point of a diagnosis: there's no cure?" Wife had a good response: "There's a big difference between looking at another thirty years with a man who has a disability, as opposed to a man who doesn't care".

John started to do his own research and found Barb Kirby's website, which gave a link to the only person in the UK at that time who would diagnose an adult. Diagnosis was duly given as clearly Asperger and the phrase "severely affected" was used in one communication. I contest that as most of the members of my local Aspie group have no job and no partner and likely never will have. John had both.

My belief is that the marriage was over at that point. To paraphrase the wife: "There's a big difference between a man who's a hard case to reform and a man with a disability who I won't be able to reform". John continued to research and learned things like eye contact, body language, and emotional contact. All good for life skills and relationships. Working on the real personality and childhood opened a right can of worms when a second personality was found.

This seems to be quite a common occurrence in the Aspie world. The secondary personality gained strength until I am now the primary and perhaps the only personality. I must have absorbed what was left of John but he isn't around any more.

## My late diagnosis experience

by Cass

Hi, my name is Cass, I was diagnosed in my early twenties after a difficult childhood of not fitting in, depression and anxiety. After going from one counsellor to another for many years one finally suggested I might have Asperger's syndrome: I feel she like she saved my life as finally having a name for what I was fighting helped me understand myself much better and made my behaviours easier for others to understand. I then went to my gp and got a referral for an official diagnosis: it took me three years to get my diagnosis at the age of 23. A lot happened in the space of three years and having an official diagnosis would have helped massively, it's terrible that anyone has to wait so long.

After contacting my gp for a referral I started university studying fine art and after two years got my degree. Because of my anxiety and dyslexia I had a lady who was with me for one-to-one support throughout, which helped massively, and luckily had fantastic lecturers who accepted my behaviour and limitations.

At this time waiting for my assessment for autism was in the back of my mind as I had started to become very maternal and discussion with my partner then started about having a baby. Well, shortly after than I was pregnant and all my thoughts were taken up with baby-related organisation. Sadly things didn't go to plan as I became very ill and the staff at hospital treated me terribly. My partner said I had autism but had yet to be officially diagnosed and they ignored him: he always has to be with me and every night we had to fight to allow him to stay with us. There were various other problems related to my Asperger's that cause major problems, so against doctors' advice I discharged myself and took my new family home. I made the right decision because as soon as I was home I started to get a lot better with the care of a community nurse. If

I had had an official diagnosis they couldn't have treated me so badly.

When my daughter was around eight months old I finally have my assessment for autism and the process was very hard and emotionally draining, but the lady who did it was lovely and that made things easier. A month later and I had the diagnosis of Asperger's syndrome: it was on my gp records and I felt empowered, like no one could tell me to stop over-reacting or stop being childish. I then applied for and received PIP (personal independence payment) and my partner was granted carer's allowance. Armed with my diagnosis letter I felt like my rituals weren't shameful any more, they were justified. For any new place or situation I was allowed to visit the building first, then meet the person, view the room and see the surrounding and exits all at my own pace and without being told I was wasting their time. I feel none of that would have been possible if I hadn't be diagnosed.

Honestly I feel it's ridiculous that I, like so many others, have to wait years from referral to assessment and so much can happen in that time. I know assessment centres are busy, but it leaves people like me stranded in a personal limbo. Luckily for myself the wait was worth it; I still struggle every day as I always have but I have also learnt so much about myself and different coping strategies to make life easier. I never felt I was ever going to achieve much out of life due to my Asperger's but since the birth of my daughter I've realised that she is my primary reason to be on this Earth, she has become my sole focus and she is my greatest achievement.

Much love to you all,



Dear AU

I thought I would write about late diagnosis as I didn't get diagnosed until I was 23.

When I was little there didn't seem to be as much knowledge about autism and Asperger's as there is today. I wasn't aware of anyone at school who had it. I had a very bad experience at school and was bullied the whole time I was there from age 5 to 16, including by teachers. I knew something was wrong with me from an early age but didn't understand what. Other children obviously picked up on my differences and made my life hell. Adults just thought I was painfully shy. I started seeing mental health services when I was 16 but still no one picked up on the Asperger's. At the time I was severely depressed because I hated my life and myself and had no idea why. I started self-harming around this time too. I had no friends and spent most of my time in my bedroom reading.

I saw so many counsellors, psychiatrists etc.: they usually said I had social phobia and depression, but it didn't seem to quite explain everything. The way they described social phobia, it was all about being scared of what people are thinking about you and worried that you'll do or say something stupid. But this wasn't my experience, I couldn't explain what it was that made me unable to communicate with strangers and it didn't explain all of my sensory issues such as feeling overwhelmed by loud noises, bright lights, uncomfortable clothing, etc. I was put on various antidepressants, none of which seemed to make any difference. One counsellor tried to make me go to group therapy which is one of the worst things I have ever experienced, sitting under bright lights in a room full of people talking about their depression. I only lasted one session and said to my mum that I would rather walk under a bus than go there again. The counsellor tried to pressure me to go every week and discharged me when I refused.

I tried and failed to get a job that lasted, some only lasted a few hours before I had a panic attack and ran away crying, I just couldn't cope

with being around strangers and concentrate on what I was meant to be doing at the same time. Pretty much every foray into the world of work has ended with me having a panic attack and running away.

By chance I got talking to someone on line who I had told some of my problems to: they said to me "Have you heard of Asperger's syndrome?" I had not, but I looked it up and finally everything made sense. My mum and I read some books and researched on line and were in tears with how much sense it made. So I was referred to a psychiatrist and my mum told him everything she thought related to me having Asperger's, going back to things from when I was a child. He apologised for not having picked up on it then referred me to the CLASS clinic in Cambridge, where I was assessed and finally diagnosed with Asperger's syndrome at age 23! We also think my dad has a lot of autistic traits so I have probably inherited it from him.

I am now nearly 35 and I am so glad I was diagnosed. I now have an explanation for the things I experience. I know why I can't communicate with strangers, why I can't make eye contact and why I can't handle certain situations. I still haven't managed to handle a job but I do voluntary work, as it is a much more understanding environment and I can decide not to go if I am feeling anxious. I also have an amazing husband who has helped me so much. His younger brother has autism so he understands a lot about my disability.

Cathy

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Dear Goth,

although I couldn't help a slight feeling of jealousy, I was most impressed about Christopher being married, especially married to a non-Aspergic. A real, admirable achievement. I want to say I wish you all the best in the future,

Tim

Dear Goth,

I read the article entitled *The nuances of empathy* in the July '14 edition of *AU* with interest and felt compelled to express my own opinion on the issue.

I feel that individuals on the autism spectrum are actually more aware of how anyone is feeling and the kind of person they are but this awareness is gained via an ability to sense it.

Because neurotypical people very often hide their feelings or intentions for one reason or another, such as because it is socially unacceptable to feel a certain way or want to do a certain thing in a particular situation, or because they consider it may be to their advantage to conceal such information from others, this confuses the individual who does not recourse to such deceit (as this is essentially what it is). In addition, those who understand these “tactics” can readily understand them (read the signs) and then accuse those who sense the truth (the denied feeling or intention) of being unable to empathise with them!

I therefore totally agree with Damian’s final point (that “they are just as bad at reading us as we are at reading them.”) but would add that I think we, however, appreciate the truth, unless we allow their “majority deceit” to “put us off the scent.”

Yours sincerely,

Ann

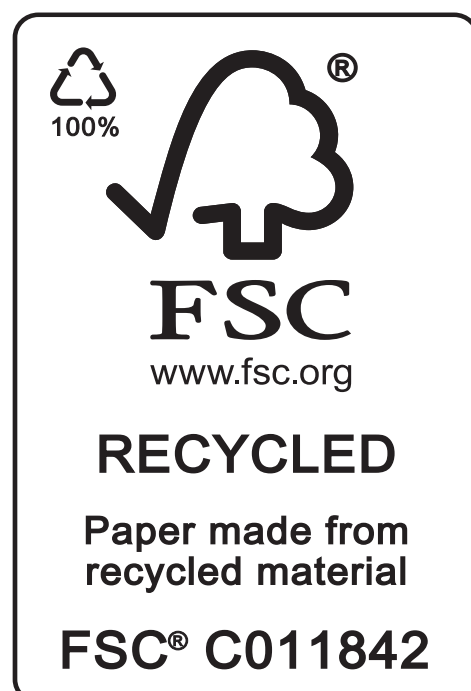
PS. I would say to anyone on the autism spectrum that they should trust their (intuitive) sense, because I have discovered from experience that it is far more reliable than reading gestural “signs”, etc.

I’d be very interested to know what others think of this.

PPS. I would also add that this “sense” can only be gained (that is, felt) when face to face with or in the physical presence of the person concerned. You cannot gain a sense of someone over the telephone, via Skype or by watching them on TV because this relies on reading gestures, so again can be very misleading.

I think it was yourself, Goth, who mentioned in a previous issue that you think those on the autism spectrum empathise more with others than neurotypicals? I think this is therefore true as we can ultimately empathise with anyone (animal or human) whilst neurotypicals tend to empathise only with those having had similar experiences and having adopted similar gestures and who follow the same cultural “codes” or rules.

*I have mentioned empathising more, though I am one of many who have spoken about this. When stressed I find it very difficult to control my empathy and sympathy, so I get worried and more stressed and on the verge of tears, sometimes for hours at a time, Editor.*



## The rules of *Asperger United*

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

- 1) *Asperger United* is funded by the NAS and readers' donations, and is independent of the NAS. Although it is called "*Asperger United*" it aims to be for the whole of the (reading) autism spectrum. That is, the concerns and joys of any subscriber on the spectrum can be printed, not just Asperger's.
- 2) *Asperger United* is free and is quarterly, published in January, April, July and October. If you do not receive a copy when you expect to, please contact AU.
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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 the NAS section of the Amazon website, please make this clear.
- 15) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.

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Friday, 21 August – Monday, 24 August 2015

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

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

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

Phone enquiries: **07511 774 654**

Postal enquiries:

Autscape  
Armstrong House  
First Avenue  
Robin Hood Airport  
Doncaster  
DN9 3GA