

Produced by and for autistic people

The *Spectrum*

Edition 99 July 2019



National
Autistic
Society

The Spectrum

The Spectrum is run by and for autistic adults (although some parents subscribe on behalf of their under-sixteens). The magazine aims to connect autistic people through their letters and articles and to share information so that they can lead more independent lives.

Please note that *the Spectrum* receives many 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. The magazine protects the identity of contributors by not printing full names unless the writer asks for their full name to be used.

The Spectrum is available at

www.autism.org.uk/thespectrum

or by paying a subscription. To subscribe you, we need your postal address. Please subscribe online or contact the Goth for a subscription form. All contact details are below. Organisations requiring multiple copies: please get in touch.

Editor: the Goth

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This magazine was founded as *Asperger United* 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. The name *the Spectrum* was suggested by dozens of people and chosen in an online poll in 2018.

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All we need is your email address and we will add you to the email notification list.

Please note that the views expressed in *the Spectrum* are not necessarily those of the editor, the National Autistic Society or those involved in the publication of the magazine.

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The Spectrum 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.

Contributions for the next issue should reach *the Spectrum* by **19 August 2019**

Welcome to the July edition of *the Spectrum*.

I find myself wondering if I am autistic, or Autistic. I have avoided the capital “a” in the past, because I was only aware of the medical use. Now that I know about the use of “Autistic” to mean that the user identifies with the Autistic community and and that the user feels that Autism is a key part of their being, I feel as though adopting the capital “a” is some sort of leap into the unknown. Does that make sense?

The Deaf community was the first, I believe, to use a capital letter in this way, so if you are looking for a wider understanding of the use of capitals, pieces written about their use of a capital are informative.

I look forward to finding out how readers feel about writing Autism, Autist and Autistic with capitals, so that the use of capitals in the magazine can reflect what writers and readers want (as far as this is possible, of course).

As ever, I also look forward to meeting some of you at Autscape in August. I know I say this every year, but it’s true: this is one of the most relaxing and enjoyable times of my year, and I encourage those of you who are nervous of meeting dozens of others at a conference to take the plunge, maybe in 2020?

Yours,

the Editor

the special interests edition – suggestion for next issue on page 13

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Was or is Elvis cool?

By **Matt**

Elvis Aron Presley – singer (1935-1977)

It's a little hard now to understand why pubescent fans went sex-crazy over the Beatles.

In the case of Elvis Presley, it makes immediate sense. The King of rock 'n' roll, as he later came to be known, was ridiculously good-looking, with a sloppy grin, darkly feminine eyes and the thick, slicked quiff of ink-black hair. In addition to which, the way he danced when he sang his songs was practically pornographic. However much he denied it (as he felt forced to, in the face of moralistic horror that greeted his rise to prominence) the sleazily athletic jerk and sling of his hips was erotic in the most literal sense. No wonder the girls screamed and clawed at their hair.

None of which is to detract from Elvis's achievements as what critics call an interpreter of song (meaning he didn't write his own stuff).

The blend of his looks, his louche stage presence and strong, high-baritone voice make him the most successful singer of all time. Add to this fact that, as a pretty white boy with a knack for outsider music, who introduced the pain of blues to the aw-shucks ease of country music, he embodied — even more than James Dean — the breakthrough of “cool” style into the mainstream.

Elvis somehow managed all this without losing his air of being a decent, straightforward

country boy from Mississippi, and one who, most of the time, just seemed to be having fun. In interviews, he came across as sharp and grounded. If anyone could handle unprecedented levels of fame, surely it was Elvis?

As it turned out, not. His legend has been strengthened by its tragic arc: from paragon to parody, and finally to parable. The one-time sex symbol became a caricature of excess, addicted to Cadillacs, bacon and banana butties, and prescription medication. He took pills to sleep, pills to perform, pills to go to the loo. Near the end, he gave a performance in Las Vegas of his ballad, *Are you lonesome tonight?* Obese, exhausted, heavily perspiring, and wired on drugs, Elvis forgot the lyrics. He amuses himself improvising some alternative words, but there's fear in his eyes, and such tiredness. He was found dead at the age of 42 at his ranch in rural Tennessee, slumped in the bathroom, killed by a cocktail of causes brought on by his prescription drug abuse.

I am biased, I think, and will always think that Elvis is cool. Let me ask or pose a question: if someone came to light today as great as Elvis, would you consider him or her to be cool? If your answer is yes, then by default Elvis is cool.

My mind is already made up, but is yours?

I left my job February,
I had no money and it was quite scary,
I took a new path on my own
and I was out of my comfort zone,
yeah, I was out of my comfort zone,
nowhere to run, nowhere to hide,

the grass ain't always greener on the other side,
I don't want to be here sitting in sorrow,
I'm gonna build myself a new tomorrow.

Gavin

Always football

by **Patrick**

Football is almost certainly my main special interest. Always a constant throughout my life but multifaceted in its nature. I not only watch football on TV, go to matches or listen to it on the radio but I also talk about it whenever and wherever possible and spend many an hour on football computer games. Outside of this I have few interests and hobbies hence I can see why my behaviour might be labelled by some as “restricted” and “repetitive”.

The positives of having this interest throughout my life are relatively easy to identify. For one, an interest that could be described as “mainstream” helped me to make and retain friendships both at school and university. I also use my knowledge of football such as tactics, players, and statistics to articulate or explain concepts in my day to day life.

Bizarrely, I have also noted that previous football matches I have watched act as a memory aid, allowing me to recall memories of what I was doing at that particular time in my life or as a marker for significant events such as weddings, births or even deaths. The

knowledge of being able to watch a game of football on TV on an evening after a difficult day at work can lift my mood but can also lead to distress and conflict with family members when commitments and football unexpectedly overlap.

I also look back at the amount of time I spent particularly as an adolescent playing football computer games such as *FIFA*, *Championship manager* and *Pro evolution* as a waste of time in terms of missing out on developing new skills, spending time with others and learning other important life lessons which I am probably just experiencing now as I enter my mid-thirties. But on other occasions playing these games (as I still do today) and reminiscing about them provides me with a sense of relaxation or stress reduction especially when I am feeling extremely anxious and unsettled.

So there you are. Football is my special interest or restricted and repetitive behaviour. For good or for bad or as a mix of the two, it has had a significant impact on shaping my life and the person I am today.

The observers

to be read forwards,
then in reverse

by **Sarah**

they smile
when they see me
so that they know
everything is calm
beneath the waves
of my stormy mirrors
(stubborn discomfort),
forgetting I have eyes
is erased and I keep
my head up, hope
this starts to mix
with all my heart
that I can tell them
and no longer feel
the need to defend
why I always have
to take my time or
do the right thing,
I am so determined to
carry on explaining
the reasons I should,
trying to give them:
“be the best” of myself
so once again it will
restore my faith
and I had begun to
feel the need to stop,
the belief I’ve gained
begins to remove
palpable loneliness

Fear

by Tom

A while ago, I had a conflict with my boss. She did something patently unreasonable and I “exploded”: I swore and left work for home. I am scared to death of conflict, so my Aspie brain immediately started reaching for the most extreme possibilities and dreamt up a worst case scenario where our working relationship was shattered and I would be forced to find another job. I even thought it a stretch to go back and collect the personal things I had lying around at the office. In the end it wasn’t nearly that dramatic: I haven’t lost my job, we talked about what had happened and decided to “put it behind us”. Sure, damage has been done to our relationship, but it hasn’t vanished completely: there is a grey area between the white of perfection and the black of abject failure. Fear had made me jump to the most extreme conclusions.

Since I was diagnosed with Asperger’s syndrome three years ago, I have learnt a lot of things, especially about fear: a very basic and powerful emotion that triggers the “fight or flight” reaction. At its most intense, it actually disrupts the normal functioning of the body by flooding it with adrenaline, thereby heightening sensory perception and muscle tension. In acute danger (like a wild animal running towards you) it can save your life: in most other situations it is next to useless.

Unfortunately, fear can be triggered by any number of abstract threats and although it isn’t always equally intense, measuring and managing fear is notoriously difficult for everyone. Prolonged states of fear can (and often do) trigger stress and in more extreme cases, anxiety. Just look at the “self-help” section in a bookstore, overflowing with books with advice on how to deal with stress and anxiety. Unfortunately, people on the Autism spectrum are extra vulnerable: emotions can be very overwhelming for us and we are often worse at managing them than neurotypicals (or “normal” people). I know

I am much worse at it than I used to think. On top of that, people on the Autism spectrum experience much more uncertainty that often causes fear. Small wonder then, that fear and anxiety are prevalent for people on the Autism spectrum.

All is not lost, though: since fear is such a basic and powerful emotion, it’s also very universal: everybody gets scared. A lot. So don’t beat yourself up when you are scared, even if you think you fear something no-one else would be scared of. Allegedly, it was Benjamin Franklin who said, “Nothing in life is certain except death and taxes.” I would like to coin the phrase: “nothing in life is certain except death and fear.” The trick is to accept that you’re scared (and not panic because of it) and then try to manage the fear. Basically you try to take the edge off by combating that awful feeling that something needs to be done and it needs to be done *now* (it rarely is that urgent: if it is — and you are in real danger — you will have acted before you start to think). Some people use medicines to achieve this, I use meditative “mindfulness” techniques adapted for people on the Autism spectrum, but it doesn’t happen overnight and it doesn’t make the fear disappear: you just get better at accepting it (and other emotions) and worry less about it. To sum up: don’t worry about worrying or being scared, it’s the human condition. In that respect we really, truly are human.

What we know, we can control — what we don’t know, controls us (walks all over us). We build upon our successes and are destroyed by our failures (infinite growth versus eternal collapse — crawling out of a black hole as opposed to falling back into it).

Tony

Pen pals

Pen pal number 286

Hi,

let's just call me MrsS, as I have an uncommon name that will be too recognisable.

I'm 33, and I have been diagnosed as being on the spectrum at 32, after a lifetime of not understanding how I work and being a source of frustration to parents, peers and boyfriends! I think I am on the high-functioning side of the spectrum and I work as a scientist in a pharmaceutical company, where the work is brilliant, but it is a chore dealing with colleagues and bosses — a challenge many of us face.

I live with my partner and my cat, and one very lonely aspect of my life is not being able to make any friends. I think I come across as too intense and too invested and it probably chases people off. I'm quite misunderstood: I say the wrong things, crave for space once I have established a relationship — all the classic things autistic people do.

I'd like to have a friend, of any age, male or female, who is understanding about my thought process and wouldn't mind discussing how normal people work and how I can navigate my life around them.

My interests: I do a lot of Reddit reading, I'm currently doing an advanced degree in engineering, I love cats and I cook very well. My obsessions span days, months or years, and have ranged from North Korea to Harry Potter and *Star wars*.

It would be great if I can start writing old fashioned letters over post/email again!

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 this magazine. 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 this magazine 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 this magazine.
- 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 the Goth, c/o The National Autistic Society, 393 City Road, London, EC1V 1NG, or email the.Spectrum@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 this magazine are opened before being passed on.

****Important notice — please read****

This magazine 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 / *the Spectrum* cannot intervene or be held responsible for any ensuing correspondence between letter-writers.

more pen-pal adverts

Pen pal number 287

Hi, my name is Sue and I'm 52 (but still young at heart ;o). I've recently been diagnosed with Asperger's syndrome. What triggered me to seek a diagnosis was watching a recent TV programme, *Chris Packham: Asperger's and me*.

Throughout my life I've wondered why I've been different to my friends and family members and I struggled throughout my school days and my jobs. Following voluntary redundancy I am now a lady of leisure.

My interests are animals, adult dot-to-dot books (I love the repetition and I find it therapeutic), reading, and watching films (horror in general), and have recently acquired an allotment.

I like to do activities that aren't group-related like snorkelling (although I don't very often get the opportunity to do it) and walking my dog.

I don't drive so recently I have acquired a bus pass, which is brilliant.

I would love to hear from fellow, like-minded "Aspergions" as I don't know anyone else with the condition.

Pen pal number 288

Sally here. I'm aged 59 and was recently diagnosed with Asperger's. I also suffer with anxiety and depression. I go for walks every day to help agoraphobia, which fluctuates between days. My interests are writing, making dolls, history, embroidery and art, among other things. I live with my partner but have no friends or social life, but now I have a diagnosis, I'd like to change that. I also have bad social anxiety. I'd like to hear from others aged 50 to 70 also diagnosed with Asperger's, for friendship, and to know how they cope. I have a very good sense of humour, and like phone-in radio programmes, documentaries and reading practical books. Paper letters, please.

Pen pal number 289

My name is Carlotta. I'm 15 years old and I live in Scotland. I'm currently in high school, and I was diagnosed when I was 11.

I have been feeling very lonely for a while now, as I can't seem to be able to make any friends at school and don't really have anyone outside of school to talk to.

My interests are reading manga, watching anime, writing stories, listening to music (specifically music from the 60s, 70s, 80s and 90s), watching videos on and learning about criminals and mysteries, and *Voltron legendary defender*.

I'm hoping to be contacted by people around the same age as me, who share similar interests to me and are also struggling to make friends.

Pen pal number 290

Hi everyone,

my name is Jade, I'm 21 and I live in England. I have dyspraxia, ADHD and am under assessment for autism. I find it very difficult to make friends so I feel really alone. I enjoy gaming, football, documentaries and music. I support Wolverhampton Wanderers, and my favourite band are The 1975. I'd like to hear from someone around the same age and start making friends!

Pen pal number 291

Hi, my name is Naomi and I didn't get diagnosed till I was in my twenties. I want to chat to other people who have gone through similar struggles.

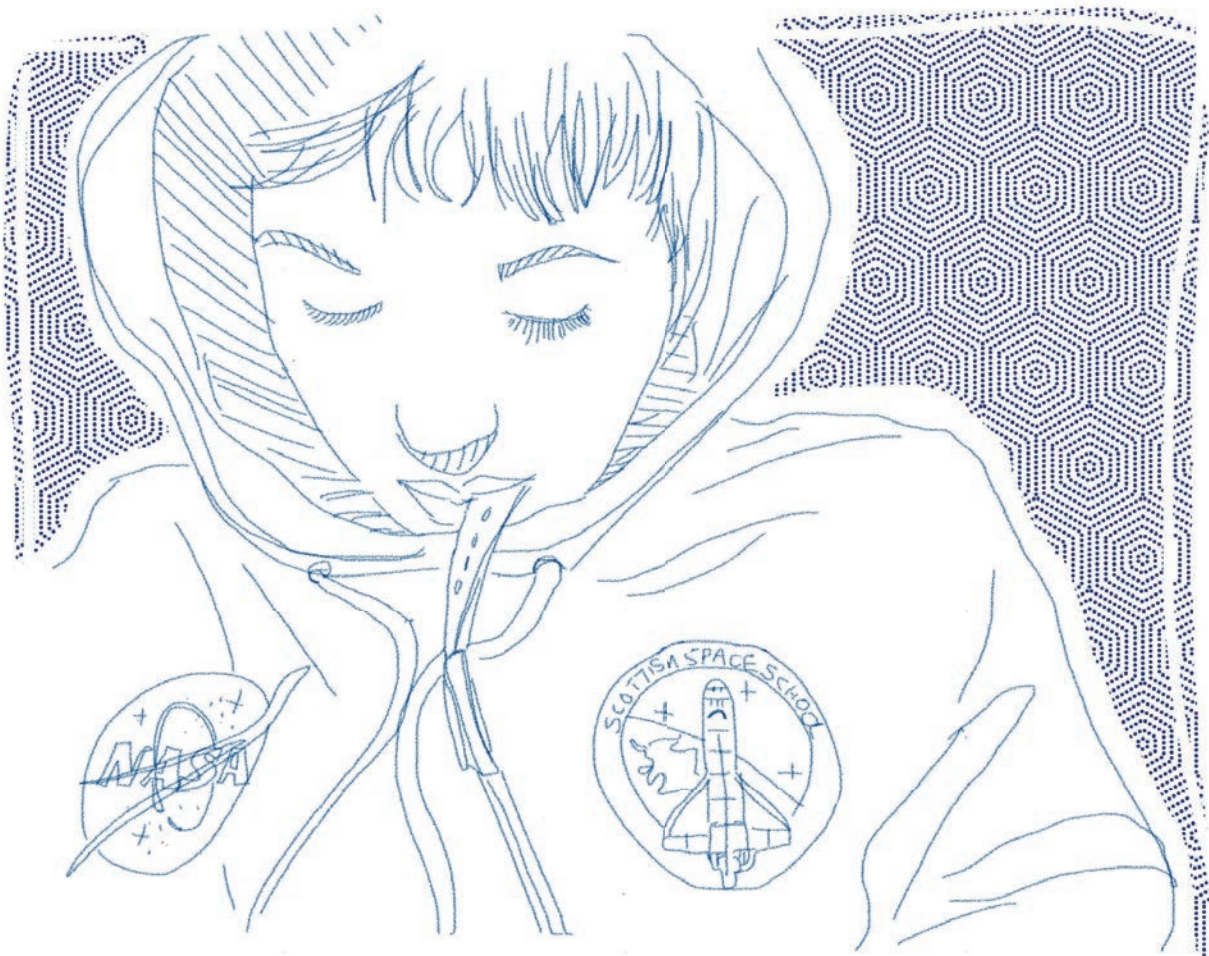
a poem, a picture, and a note from the creator

An autistic dance
Is a tap, rap, hum
Of a finger drum
And a clicking tongue

An autistic dance
Is a jump, skip, hop
And a spinning top
Never seems to stop

An autistic dance
Is a song of “eeeeee”
And a swinging glee,
And a joy to see.

by **Sophie**



This is me with one of my favourite stims, chewing on my watch. I'm also wearing my space school hoodie, as space is one of my big special interests.

letters to the Editor

Hi Goth and *Spectrum* readers,

I read with interest the article by Bruce, *The Asperger's syndrome victim*, in edition 97. Especially the part about wanting to create a good impression by giving women in shops cards — Christmas cards with a positive message. I think us Aspie men, and maybe women, can be desperate for companionship. I write poetry and have just gone up to people and given them poetry. I'm not sure why I did this. Maybe I wanted to make a connection. I wanted to be someone popular and respected and liked. Mine was a very eccentric way of doing this. I wish Bruce well in his quest. He sounds really nice and it's been difficult for him because he has been bullied and found connecting with others hard.

I was very shy at school so I tried to act more tough by going up to other boys and asking them for a fight. My differentness has manifested itself in many different forms.

I would be interested to learn how Bruce gets on in the future, if he ever writes an article again. I felt very different at school. Even the other socially different people would make fun of me. I talked funny as well, I think because I had goofy teeth and children at school would imitate how I talked in a mocking way. But I don't blame them for this. I don't hold a grudge because they were nice to me sometimes. But I do understand, I hope, that it can be difficult to let these things go at times.

Sorry to hear about Bruce's asthma. This probably affected his education. And I have trouble retaining information too. Mine might be a different reason: sometimes I drift off if someone is chatting to me and there is a lot of information to take in. I can't always remember the details of what I've been told.

But I have a girlfriend now, of five-and-a-half years. She is lovely. We go all sorts of places: bottle-fed a lamb, took a donkey for a walk. Go out for meals regularly. I always wanted a girlfriend. I was lucky. Love found me after I stopped trying to find it. I wish Bruce and all

the *Spectrum* readers and you, Goth, success, love and happiness. I thought I'd write to you because I like writing and it helps at different times in different ways to express myself. I have many obsessions. I would be interested if any of your readers knew how to tell the difference between OCD and an "Asperger's" obsession.

I write lists a lot to try and motivate me to do things. I enjoy exercising but I feel a need to write about the length of time I exercise for and what distance I do on the exercise bike. But this isn't a problem, so maybe isn't OCD? But I might not be motivated to do it so much if it wasn't part of a project. I count the number of days I exercise, tidy, Hoover my bedroom. In the past three-and-a-bit years I have done 641 days. I also count the days I see my girlfriend. I see her three or four times a week. I count each day I see her as a date. At the time of writing I have had 827 dates with my girlfriend, but I love counting these so maybe that isn't a problem.

What maybe is a problem is having to count and write down the time and date of when I brush my teeth and tongue; I've never had great dental hygiene. And I'm trying to do something about that, but I'm scared to go to the dentist. I fear the possibility of having to have fillings or teeth removed. I also worry about contracting HIV from dental equipment. It's probably irrational but the thought is still there — I find ideas I get into my head can stay there for years.

I feel quite happy a lot of the time but I do get overloads if I feel too much. Before I had a girlfriend, I would feel overload if I spent too long with a woman I fancied. I'm not sure why, but I've always been oversensitive. Recently, I get overloads if I discuss my diet too much with my girlfriend, as I lack self-control sometimes to resist dessert and alcohol. We both really like cake, but who doesn't! Lol. We both go for meals quite often, once, occasionally twice a week and we'll have dessert. Sometimes my girlfriend will go for a pudding like a crumble or a sponge which is probably less Calories than a giant piece of cake. I'm probably on the spectrum somewhere of having an eating disorder: I'm obsessed about

letters to the Editor (continued)

my weight and how I look. But I'm six-foot-one-and-a-quarter inches and twelve stone, eleven pounds so probably technically not overweight. The overloads come from discussing my problems with my girlfriend or family. My girlfriend loves these treats but also wants to encourage me to lose weight. She'll support me in this but I know she loves these things so much and I'm so happy when with her that I want these things too. Plus I don't want to deprive her. I'd feel bad if I did that.

I've been trying to make new friends and it's mainly via letters. I'm in a bubble with my girlfriend, and then in another with my mum and dad. But I want to break out of it sometimes. I'm quite controlled by numbers. I draw a coin out of a box and the last number on the date tells me how many activities to do. If I draw out a coin with the last number above a five, I try not to draw out any more during that day. My aim is to get to 150 coins drawn out in total. The reason now that I do this is because I have an OCD thing with tearing things up and throwing them away, mainly my writing projects but I'm keeping in mind this target of 150 and I'm not to do this until I've reached it. In the past I've struggled to stick to things. In a previous incarnation the idea of drawing the coin out was to motivate myself to do the activities but I don't have that problem as much any more.

In the past and to a certain extent I still do, I had an obsession with the number five. If I cried five days in a row I would try and change my focus by creating new projects, often writing. It was like the freshness of a new start. Plus it was trying to deal with adversity. I would often cry because of feeling overload. However, I started writing down when these five days in a row or five times in five days or less occurred. I got too obsessed with crying. I've not fully analysed this but it became too important, the crying did and the number five got contaminated. The writing about the times I cried made it seem too real, if that makes sense.

I've often liked the number 25 and as an offshoot from this I got obsessed with the number eight because eight days in a month is

just over 25% of the days that are in a month. I have what I think a psychologist would say magical thinking and OCD around numbers.

I'd probably better stop there. But I'd love to hear about other people's obsessions related to numbers and what their thoughts are on anything I've written. I apologise if any of it is difficult to follow. I have many obsessions and I feel they are interlinked in some way. I need numbers and structure in my life. Is this OCD or Asperger's or maybe both?

Love,

Daniel

Hello Goth and all *AU* readers,

spelling is not my thing. I use a dictionary (the word "dictionary" is an example — I would have gone with "-ery") all the time to check my often-wrong spelling. I was told that the computer has some sort of automatic correction device, but it has not made itself known to me.

But I wonder if it is an Asperger's thing to see the correct spelling of words but not to like the look of such words. For example, I have recently written the following words: hugs, tried and been. They do not look right to me. I know they are right — I checked them in the dictionary (more than once) but these words just look wrong to me.

I know from reading *AU* that people can describe some oddities which I slowly realize (this word "realize" also looks wrong to me) are common to me. Are wrong-looking words something common to some other individuals with autism? Note: I assume this has nothing to do with dyslexia as I had no difficulty (this word "difficulty" looks wrong to me) in learning to read and I have no difficulty in reading. I have never read a book — but that is because they are much too long.

Michael

A horde of inaccuracy and fearmongering

by **Abi and Virginia**

In 2016, a film called *Split* was released as a follow-up to Bruce Willis' *Unbreakable*. Until the end of this film, when Willis made an appearance, the link was not apparent, but in the last few minutes it became clear that there would be a sequel once more. The film that ties them all together is *Glass*, released this year, 2019. We have seen all three, but this is not just a film review.

In *Split* the main premise is that the antagonist has dissociative identity disorder (DID), formerly known as multiple personality disorder. One of the writers of this article, Abi, has DID (she wants to assure you that “not all of us are writing this, just me”) and she wants to put the record straight by giving an insider's perspective on these movies and dismantling some of the negative stereotypes attached to this disorder.

DID is formed by extreme and repeated childhood trauma and is diagnosed when two or more distinct personality states are present along with amnesia of these personalities. For as long as media has existed it has been used as a plot twist in horror movies and thrillers, for example, *Psycho* and *Fight club*. This trope has been incredibly harmful and has caused a negative stigma

around a disorder which is simply a survival mechanism. In the film trilogy, it's all very well to turn the story into a fantasy comic book superhero scenario, but the negativity surrounding DID is very much present, particularly in the last two films.

Kevin Wendell-Crumb, the antagonist in *Split*, applies a collective noun, “the horde”, to his alter-egos. Arguably, some of the ideas represented in the film are rooted in fact: Wendell-Crumb suffered abuse as a child which caused his disorder and certainly it is not uncommon to name your “system” (the professional term for the group of personalities, which are called alters). James McEvoy's acting most certainly cannot be faulted — the audience is very aware of which alter is in the room by extremely subtle shifts in character and expression, not just costume or voice. But why does he have to be the villain of the piece?

Although alters are real people, as morally “grey” as anybody else, it seems deeply stigmatising to have an inherently evil alter constantly portrayed on screen. Most people enjoy a horror or suspense movie, with twists and surprises — when *Psycho* was released it was a new

concept with an amazing twist. However, using DID to create a thriller seems almost lazy these days, especially considering that this is a very real condition.

In the *Split* trilogy, *Unbreakable* is a “superpower” film, *Split* is a thriller, and *Glass* is somewhere between the two: it seems unsure of its genre, and the use of DID cheapens it. If audiences are uneducated about DID, their only knowledge comes from these films. Abi remembers old friends, upon discovering her DID, who made remarks like, “Don't let your serial killer out!” There can be subtle discrimination, where people can begin to avoid the person. However, it should be acknowledged that for all its flaws, *Glass* portrayed a more sympathetic and slightly more accurate depiction of DID than *Split*. The alters are developed as more multi-faceted and there is some genuine sympathy for even the “evil” alter-ego. On the other hand, one of the more harmful messages of this film was the portrayal of therapists as the enemy, and quite inept. The therapist exclaims that twenty-three alters is unheard of, yet in truth the amount of alters in any system can vary from two to over a hundred. The average number is thirteen.

an article (continued), a letter, and a notice

The most harmful act one of Abi's alters has ever done is steal food from the fridge, which got her into trouble!

Recently, a more accurate portrayal of DID has been showcased in DC's *Doom patrol* in the form of Crazy Jane and her sixty-four alters, all with different superpowers. This proves that you can have an honest portrayal and still have a great superhero story. Another accurate characterisation, in *Mr Robot*, is Elliot, the protagonist of this TV show. He only has one alter, but is just as sensitively written as Jane. Both of these are the product of extensive and thoughtful research, unlike Kevin and the horde. The director and writers of *Split* were offered guidance and help by both people with DID and therapists, but turned them down.

Maybe it's time for a film or book written by someone with DID, or even a blockbuster that portrays it in an accurate and more positive light. What an intriguing story that would be!

I find it almost constantly dispiriting that Hollywood and also authors, when depicting a little-understood, "fashionable" condition give the condition to the antagonist or villain, for example, the criminals in House rules (by Jodi Picoult) and The behaviour of moths (by Poppy Adams). I am interested to hear what other people think, Editor.

Dear Goth,

I would like to submit something, I hope you don't mind? It's something I wrote on Facebook and thought you might like to share it for your readers.

"So . . . autism is a spectrum. Like the result of a prism splitting light into its different components, the invisible ones too. All we need to do is wear the correct shades to see the invisible spectrum. If we don't know how to make those shades, then we need someone who can. That person is known as an advocate.

"Advocates are very rare for autistic people.

"They have a super power. If they can't make the correct shades, then they do the impossible. They turn the prism inside us to shine the split light a different direction and try to filter a specific colour. This helps us try to focus on that specific task the colour might represent.

"Sometimes we get so overloaded we might even forget to eat or forget to consider that a close friend's relative has recently died or fail to realise that we put on odd socks . . . so the advocate moves the prism so that we focus on one detail. They show us a big juicy burger, or remind us how to be mournful and sincere, or put the right pair of socks together for us.

"It might seem simple, as something you might be familiar with, putting on odd socks accidentally. And this is where it gets difficult for me to distinguish my disability from "normal" life. That's because no matter how I try to explain it, I need an advocate to show you the invisible that I am desperate for you to understand.

"Mental illness is invisible disability. What you might see, hear or feel is completely different from how we demonstrate, vocalise or touch. Don't judge. Try to help instead. Thanks for reading."

Wolf Morningstar

If sufficient material is sent in, the theme for October will be **socialising and loneliness**. I know that this is both an opportunity for great happiness and a big problem for almost all of us, so anything about how you find happiness is appropriate. I am also aware that it is a huge area, including hobbies, pets, friendships, families, work — nearly all of life usually involves socialising, even complaining to your bank. 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 *the Spectrum*, the best way to change it is to send something in!

I stim

by Katrine

I sit. My form is transfixed as though tightly contained, taped to this chair, overwhelmed by its mindfield of paisley upon rust upon black. I cannot escape. My thoughts run wild: da-dum da-dum, da-dum, you are *such* an idiot, stop, Annie, stop, these are a few of my favourite things, ahhhhhhhhhhhhhhhhh, a figure of eight crashing before my eyes in a harsh white light, a crescendo, all competing for my attention in unison.

I think therefore I am? I think therefore I am now seems more appropriate. A chemical, a hormone, charging through my veins. The adrenaline, I think.

But why this betrayal? I fear unveiling my brain for what it truly is. I would hate to unsettle their precious domestic ambience.

Stay calm, Annie, stay calm. She only spoke to you, she wanted the best. Small talk is to be expected at such gatherings, you told yourself before you came.

The underside of a neighbouring chair is dappled with a rhythmic interchanging of soul-invading colour, red, blue, red, blue, red, blue. It reflects from the flashing lights hung upon the hearth.

My left leg kicks as though in combat, right, left, right, left, red, blue, red, blue. My left finger is lodged within my mouth, right, left, right, left, red, blue, red, blue. Lights are just one of the festive extravagances I could do without: they burn inside.

I search for consistency in the hope to ground myself — I should know what to do by now.

My uncle asks me if I want a drink, “Annie, Annie,” he says. I’m not there, I’m within the realms of my own internalisation.

It took him many attempts: you’ve got to have the patience of a saint, they’d say, but I came round in the end.

No thank you, I stutter, fingers still inserted between my tongue and teeth, still moving from left to right. I never say, “thanks”, it is always “thank you”. Linguistic eloquence is important to me. I am a prescriptivist.

My throat throbs, not from screaming but from trying too hard to conform and it pains me to speak. I want more than anything to converse, to preserve my presentation of normality, to be taken seriously.

The others said they would be arriving at 5.30pm: 5.44pm and they still have not emerged. I sense that the arrival is imminent but nobody has told me. By this point I have been revising the potential discourse I supposed would operate between myself and these members of my extended family for the past fifty minutes, over and over after having constructed it whilst I could not sleep in bed the night before. I am a categorical being, a collation of many varying personas that I must unmask in differing situations and right now there is a dissonance between my adopted persona and my locality. I am prepared for engaging in conversation with others my own age but remain surrounded by my elders. The two versions of myself that I put forth in these situations are markedly removed from one another. A cause for heightened panic.

The small interim of discourse that operated between myself and my uncle has opened up a small gap in my right-left-right-left-red-blue-red-blue cycle so I sit and try to muster up the energy to make my exit. I turn my back. My panic-stricken face is not up for obtainment by those around me, I do not wish for a place in their mental gallery. My madness is no picture, no art.

a story (continued) and an article

I reverse as the finger in my mouth continues to wriggle, my thoughts are on reaching the double doors to my left, their clear glass a haven.

One step further and through the face of this glass I see a wisp of my cousin's hair as he turns the corner onto the hallway where I stand guarding the entrance. The pace of my breath increases further still and my thoughts are intangible. I want to scream, to release, to rid myself of this detrimental presence, to align the incessant screaming in my head with that of my own out loud. I hope for my exteriority to be congruent with my interiority so as to reach a refreshing state of consistency. I am restrained by a myriad of societal expectations. I am in no position to talk.

I run, any exit, hideaway, place of concealment I aim for whilst my mind battles against me. The bay window. I hide myself away and a force within me unearths a repetitive screeching, ahh ahh ahh ahh ahh, the pause between as obliterating as the outburst itself. It accelerates and I can no longer stop, I can't breathe, a personal attack over which I have no control. I

suppress with all my might, stifling my screeches, I mustn't let anybody hear me, they will think I am mad.

I persist for what feels like half an hour, I cannot be sure precisely. I wait for my mother to encompass me. This pressure is the only means of reassurance that I can access: relaxation cannot come from within. My mother navigates me and takes me outside as I struggle for breath.

Out of the realms of judgement I run, skip, revert myself back to the ten-year-old that I embody but must contain within. I want to be liked by everybody and to be liked requires normality.

My mother and I sing songs from my favourite musical, my own rendition in a tone contaminated by the voice of a little girl, the little girl that I am. This self-expression is cathartic.

I think to myself: is my life what dying feels like, outbursts of suffering that terminate with unity?

I just carry on stimming.

Max

by Elkie

We are so tuned to each other that words are unnecessary. He senses my mood and knows best how to respond to it. If I've been impatient or unfair, he never takes long to forgive me. When I come to his house, he jumps up enthusiastically and presents me with the first "gift" he can find.

We love to go out together, Max running by my bicycle, either to the woods or the river or just to the park round the corner. When we get home we share a bite to eat and cuddle up on the rug. While Max grunts his pleasure, I make my own sounds, made-up words repeated in a soft voice.

One day a vendor came to the door. Max insisted on standing beside me, ready to give

his life for me if the stranger was in any way to appear threatening.

When we have to part, Max's face always gets that anguished look which makes me want to hug him and never let go. Last week I was away for a few days. I had a great time climbing mountains. But I missed Max. My heart felt heavy thinking of him, his sad eyes watching the door, anxiously listening out for my steps on the gravel. It hurt, both of us. I would have explained it to him: "Four days away and then I'll be back", but words don't mean much to Max. He just wants to be with me and I want to be with him and burrow my face in his soft fur. It's the closest relationship I've ever had.

Alexithymia – a personal journey

by Andrew

Alexithymia. A new word for me. A new word to get my tongue round and to understand. Alexithymia is the name for a condition that means people affected by it are dysfunctional regarding emotional awareness, social attachment and interpersonal relating. It is a condition that co-occurs with autism but does not share the same symptoms. Researchers are constantly debating which symptoms are related to autism and which are related to alexithymia. More can be read about autism and alexithymia and how they co-exist with each other by following the link:

sites.google.com/site/geoffbirdlab/home

In layman's terms you have no words for anything, no emotions, nothing to say and nothing to talk about. It can be as if you are a shell just existing and literally going through the motions until you die. You have no life and spend most of your time alone wondering why you are the way you are and why people shun you. It drains you constantly wondering why people avoid you, don't talk to you, cross the road to avoid you. You have no energy left to deal with day-to-day life. All you do is exist for reasons unknown to you and to anyone around you. You have no purpose in life, no reason to exist. All you can do is wonder why . . .

Dr Rachel Moseley from the University of Bournemouth describes alexithymia as: difficulty identifying what you're feeling, difficulty describing what you're feeling, and an externally orientated, "stimulus-driven" thinking style (which means that people with alexithymia don't tend to be introspective about their feelings and emotions nor spend a lot of time thinking about how others might be feeling — because emotions are very confusing to them. They therefore tend to think more "concretely" about things that are going on (that is, *external* stimuli in the outside world rather than *internal* feelings). And she adds

that this is the most common view but not the only view. This is a view I can relate to from my own personal experiences.

In my personal experiences I have been shunned by people at work and in social situations. In relationships I just sit there, at the most wondering what to say or do, usually just staring blankly at a wall ignoring the person I'm with. It's no wonder I'm single. How am I supposed to respond to questions of how I feel when I cannot interpret any feelings I have? And what happens when you don't feel anything? How do you answer someone who asks you how you're feeling when you're feeling nothing at all?

Conversation does not come easy to me. I struggle to keep up with what is being talked about and quickly lose interest preferring to do anything but converse. If someone has a baby it's so what, people buy a new car and I'm wondering why they are so excited, they got a new job or a promotion and I'm wondering if they will be so excited in a year's time. I'm not interested right now.

Even if people are ill, injured or dying there's barely a flicker of an emotion. Life goes on and these things happen. At funerals there's no tears. I go because I know it's expected, a social norm and because I know it means something to my friends. This could be seen as pragmatism and stoicism at an extreme most people cannot comprehend.

And yes I've felt lonely, isolated, anxious, stressed and depressed all because I did not understand why some people wouldn't talk to me, why some people shunned me, why I found social situations difficult, why I didn't behave and express myself the same way other people did naturally, why no-one wanted a relationship with me, why I felt different and not in step with the rest of society. This is when you're at your lowest, everything is too much to cope with.

an article (continued)

After years of trying to find a purpose in life I did: study and research. I started an access course at college and now I have just started a PhD — the highest qualification you can get. I have found something I enjoy doing and something I feel that I am good at and that is worthwhile.

I was diagnosed with Asperger's syndrome at the age of 41 in 2008. This answered many questions, filled in gaps and helped me to move on and understand myself and others better. There still seemed to be something missing but I assumed it was my Asperger's being unique to me and got on with life still wondering about some things and still making some mistakes the same.

Then this year I was diagnosed with dyspraxia and this helped move things on a little bit. A lot of it crosses over with Asperger's but there was still something missing, one more gap to fill. Then Rachel Moseley emailed me the results of some research I had taken part in about autistics and self-harm and here was a new word, alexithymia.

I read about it and I recognised myself in the description. All of a sudden it made sense why I was the way I perceive myself to be. Why I find social situations difficult, why I feel emotionally detached and why I find it difficult relating interpersonally. The final gap in my personal identity had been filled and I had a name, a label to attach to my feelings and identity. I could call them something, read about them and understand them. It's how my mind works.

I felt that all the anxiety, stress and pressure had been lifted from my shoulders. No longer did I need to try to fit in and try and be someone else because I could not and cannot be that person. I can only be me. I don't need to try anymore I can relax and let the things I cannot control go and concentrate on the things I can do.

I understand now why I struggle in relationships and social situations and why I don't feel emotions the same way others do and I'm fine with that. I get why my supervisor at university says they want to see some enthusiasm from me and then stare at me wondering why I'm

just sat there staring back at them blankly. I now understand so much more about myself, people and life and all because of one word.

This means I struggle to understand why some people seem to get on with others and make progress effortlessly, talking to others, making friends, making contacts, whereas I struggle with these interactions and am often left at the edges of discussions looking on, wondering what I need to do to get my voice heard and feel involved in society. This includes my autistic friends too. Many of them have social skills that I am envious of and I can only stand and wonder at their ability to start and hold a conversation with others.

One skill I do have is that I can write. I can write about how I feel and what I see going on in society far more effectively than I can talk about it. I don't know why this is, it's just the way I am and I've long got past the point where I would worry about it. I can read theories, apply them to autism and write about them. Once I've written about them I can talk about them all day long, until the topic changes and then I'm lost.

I am lucky too in that I have a good and varied circle of friends and now I see them in a new light and realise how lucky I am to have them. I am also very lucky I am studying, and if I'm having an off day I can stay at home or go for a run over the moors and get back to being myself.

I understand and appreciate that not everyone would feel the same way I do. I know people who don't like labels and are always trying to fit into society in as unobtrusive a way as possible and all they want to do is to feel accepted and that they belong. And I have been there too fighting a constant battle to be accepted and understood but it was a battle that drained me of everything.

Now I'm just myself and if people like me they do, if they don't, they don't. I understand myself now and understand why some people like me and some don't. I feel so much better and I'm sure people notice because more people are saying hello to me and smiling at me. It's amazing how one word can change everything in your world.

Spring, stimming, and meltdowns

by Tony

Spring! I have finally clicked on something new, just the other day and that is odd symptoms I had previously but never connected with anything in particular I now have. One of these is full-body stretching in bed, like you see kittens do in front of a fire. Another is itching in my right hip area. A further symptom is blood pulsing in my left ear as a noise and a feeling in my left instep. I put all of this down to Spring and coming out of semi-hibernation. Think of butterflies coming out of a cocoon and how they pump blood into their wings. The cocoon is Winter shelter. Look how flowers burst up through the soil or out of the hard wood of branches, when better weather comes (the warmth of the sun and longer days in which this is achieved).

I have also realized that this relates to getting older as some of this is painful or discomforting as blood is pumped into areas it was withdrawn from, in response to the cold. It is like when your hands get cold and numb then hurt like blazes when they start warming up again.

I have also realized that mucus build-up, like wax in the ears, is a sign of substance intolerance and defence by the body in trying to shut out such

unwanted material (pulling up the body's drawbridge and shutting the door on further invaders or hostile weather).

I wonder if sensitives like me may make good experimental subjects and whether hypochondriacs are like us but worried about the significance of their symptoms, instead of having a scientific curiosity about the causes?

It is funny how several correspondents talk about meltdowns in the April issue, though they use different terminology. David, in his piece about fear, calls it a mega-mindquake, Willow calls it falling down the rabbit hole*. I had a case of it this very morning when printing something and trying to fill up the paper tray while the machine was still feeding sheets in. The printer jammed and I went ballistic, shouting at myself and frantically pulling out the jammed sheets, going from mild-mannered David Banner, to the Incredible Sulk (or Mr Angry) in seconds. I think this is down to the perfectionism and OCD that Ita mentioned in her response to Bruce from the last issue (Gene Wilder and his comfort blanket, in *The producers* — yes, that is us and it is normal for Norfolk, where, funnily enough, I come from). Like

Katrine, I noticed that my sensitivities are getting worse with age and again referring to Ita's partner: yes, I wash my hands then I wash them again. Stimming and ticking (yes I know that is Tourette's but I am getting that as well as time goes by) are also increasing as I age. It irritates my wife when I twiddle my thumbs (never used to), scratch the palms of my hands, crack my joints or show signs of restless-leg syndrome. Explosive, hypersensitive knee-jerkers — who in their right mind would want anything to do with us, I'd like to know?

* After an explosion, my destroyed world falls down inside myself, like a mirror smashing or Humpty-Dumpty falling off his wall of apparent normality (and his partner realises that their relationship has hit rock bottom again).



stuff you might like to know about *the Spectrum*

The rules of *the Spectrum*

(contact information for *the Spectrum* is on page 2 and again on page 20)

- 1) *The Spectrum* is funded by the NAS and readers' subscriptions, and is independent of the NAS. Although it was 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.
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- 14) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.

Pets

by **Matt**

Although I'm 28, I've never had a pet of my own, but have grown up with pets around me.

Throughout my childhood I grew up with my nan's dog, Cindy. A black poodle, she was affectionate and would run to you no matter who you are, or whether or not she knew you. Cindy, as I say, was a very affectionate dog, she'd intuitively know when something was wrong, or if you were having a down day, and she'd be glued to your side: Cindy would follow you, cuddle up to you and without fail I'd always feel better quickly.

During my early teens I was in and out of foster

homes all of whom had pets of some sort ranging from dogs (Shih-tzus) to snakes, tarantulas, guinea pigs and even chickens — yes, chickens. Although I've not had a pet of my own I've felt like I did, as I took responsibility for these animals, all of them, even the tarantulas, and I'm an arachnophobe!

Recently I had a dream about having a pet. I looked into the meaning of dreams and one book that I found states that a dream which contains pets mirrors the instinctive ability to nurture plans and ideas that are close to one's heart, so we can develop them with love and affection.

Thinking out of the box and putting it into my life at the moment, the definition above I can relate to, as I have plans at the moment: I'm starting an Open University course in art and languages, an access module, but the plan is afterwards to go and do, a degree (BA, Honours) in Arts and Humanities. It reflects my interests really well and I can totally relate to it.

One day I will have a pet, I don't know what, maybe a dog, but I'm sure I will have a pet one day. If I do have a dog I feel very strongly that I'll more than likely get a Rhodesian ridgeback or a standard poodle — I love these breeds.

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