Produced by and for Autistic people

# Dectium Edition 102 April 2020





The



# 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

National Autistic Society production support: the Content Team

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

NAS database support: the Data Services Team

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.

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

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Tel: **0808 800 1050** (free from most landlines) or

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.

Tel: 020 7923 5779 (geographical charges apply)

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.

**Welcome** to the April edition of *the Spectrum*.

Changes are happening around us, most noticeably for me Brexit and the Covid-19 flu pandemic, and Autists have long been characterised as having problems coping with change. But of course that's not really true. Just like anyone else, we have problems coping with unexpected stresses — it's the uncertainty that people, all people, Autistic or not, struggle to cope with. I think we differ only in the sorts of changes that we can foresee, having had very different upbringings and life experiences

to typical people. And very different sensory environments to most people, with no allowances made, usually, even in specialist settings.

So I think now is a good time to bring our anxieties and coping strategies over uncertainty out into the open and see if we can help each other.

As ever, I will look forward to the postbag.

Yours,

the Editor

# the conforming edition — suggestion for next issue on page 9

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# Conforming to the workplace

#### by JM

I started my job some years ago, and although at the time I thought it was okay, in retrospect my job started badly. I was told by my advisor at the time what the salary would be. However a few weeks after when I queried my pay I was told that the salary was £6,000 less. I really wish I had the confidence to question it.

Soon after, I overheard a conversation that went like this: "If JM's Aspergic, can he use the phone?" The other manager said, "Can you imagine?" then they laughed. Later the second manager, whilst I was on the phone to a candidate, put their finger on the button to cut off the call and said, "You answering the phone is under review." It's been years of me not being allowed to answer the phone, which I find degrading and awful. This company has destroyed my confidence.

The following year two other events happened. I had the opportunity to apply for a higher-level role: the only feedback I got from my manager at the time was, "Your interview is a boxticking exercise." All the support staff were invited to a big awayday because there were major changes, including on IT systems: I was the only one left out of this training day.

I eventually did the training spread over two days, but I had to do it by myself with no help from anyone, I also had to carry on working and checking the training manual as I worked. I have been asking for years for training, to do my job properly.

A manager's friend employed by the company said in front of someone I was about to interview, "He cheats on his partner." I had to carry on the interview, I had to ask someone to interview the candidate halfway through because they said, "I was cheated on by my husband, I don't know what to say to you."

Recently, as I had so much to do, I asked the HR manager if I could sit down in another, empty office. The main director ran over to me and said, "What do you think you're doing?" I said, "Sarah said I could sit there as I need a quiet space to do all this work." He walked out of the office and came back seconds later (impossible to walk to the other side of the second office, have a conversation then walk back and talk to me) then said, "Go back to your seat." This director has in the past whistled at the other disabled person in the office to go out and get him lunch, and will throw items of post at me and

expect me to catch: one time a box hit my face and he said, "You need to catch". When his father came into the office he felt the need to bang his hands on the reception desk and say, "That man lives in Mayfair." Good for him that he has a rich family but I struggle to pay my rent; it also shows money does *not* buy class.

I am not one to lord over the fact that I have Asperger's syndrome but the only reasonable adjustments I need are: training on our IT system and to be allowed to answer the phone: I have never been rude to anyone on the phone, I point out, because then it would be understandable why I shouldn't use it.

Now they want me to end my employment in exchange for a few months salary. To be disabled and unemployed in this climate terrifies me: it was three years of being unemployed before I found this job. It also sickens me that a huge corporation would rather pay thousands to let me go rather rather than pay £200 for a support worker for eight weeks, coming in once a week so I can finally do my job properly.

I also want to say that I don't have any malice against my current employer, because

# feature (continued) and a second feature

even though I am soon being forced to step down, I am grateful to have had the opportunity to work in a sector I love. I do know that after this experience I will need help in finding a job: my parents are also trying to help me find a psychiatrist because I know that after this I will need this help. I fully intend to stay in this sector as what we do for people is great.

Luckily, I'm being kept afloat by lots of love from friends, family and lots of music.

In the NAS leaflet, *I am Autistic*, it says disabled people will struggle to find work or keep a job due to unsupportive or misunderstanding managers, and the fact that I have been treated so badly by an organisation is an absolute scandal.

All I've ever wanted was proper training, a decent salary and to use the phone.

#### (conforming)

The notice for this issue said that the theme would be "conforming and why we shouldn't have to do it". Why? Because we already are. Far more than people realise. As with LGBTQI+ emancipation, I think it's much more important to educate people on how much we are already conforming to "un-autistic" norms. But also to educate people to understand that it's entirely natural to feel uncomfortable about that because "our" behaviour can be far removed from what is considered "normal", but that feeling uncomfortable is not a reason to condemn the people who make you uncomfortable. A notion, by the way, that in itself would have saved history countless tragedies. Conversely, it may allow people on the spectrum who - like me, and I suspect many others, tend to rein themselves in a little overmuch — to loosen those reins just a little and feel more comfortable with themselves - and others.

We humans, autistic or not, have two competing but inextricably linked drives: on the one hand we long to be "part" of a group. This gives us security (in numbers), validation (these people are just like me), but also requires conforming because groups (and by extension many other organisations, with cults and bureaucracies at the extreme end) create their own dynamics which need to be maintained if the group is to survive. On the other hand, we crave to be individuals, to feel accepted and validated despite what sets us apart from the group. And also celebrated, if what sets us apart is a singular talent. There is a

constant tug-of-war between these drives, both within ourselves and in societies. My instincts tell me, however, that the current emphasis on acceptance — in some parts — of people as they are (and thus a move in the direction of individualism) is the right one. Both Twentieth and Twenty-first Century history in general and the recent coupling of the bureaucracy that was the result of that history with technology that relies on algorithms (which are in essence just an extreme form of bureaucracy in that they try to squeeze all of life and humanity in easily identifiable categories) have resulted in a trending toward the group end of the spectrum. Ironically, much of the emancipatory movements during that same history (women, people of colour, people of different sexual and eventually gender identities and hopefully also people of different neurological identities) have just been trying to create new "categories" within the system that better reflect their individuality.

On a personal note: for me "autism" means that there is an entire field of study devoted to the problems I run into and a lot of people who try to help mitigate those problems. Added to that is the realisation that those problems are therefore not half as unique as I thought they were: I am not alone. Or crazy. As regards to society and groups, I don't perceive "autism" to say something about me, but all the more about a society that needs such a label to understand (or accept) me.

Tom

#### a letter

Reading Aiden's piece, Both sides of the coin, it felt almost like a poem. I resonate with so much of it, too. I wouldn't say I don't feel the cold but it doesn't bother me enough to stop me. If I am hot I don't think to drink, or didn't, but as I have got older, like the cold, I know what to look out for as something that isn't good for me (68 last birthday). Hunger? I listen for a rumbling tummy. I too notice myself getting irritable if I haven't eaten or not had enough sleep. I do feel pain but I put myself through it to relieve the tension by sending my muscles deliberately into cramp. I get injections for B12 deficiency, every three months, but it doesn't faze me. I wouldn't want piercings or botox if I was a woman —- just not my generational thing. Bustling crowds, and public toilets, drive me round the bend. I hated dances and discos when I was a teenager because of all the loud noise. Constant noise is fine but like David, sudden bangs, idiots screaming, revving their car engines or screeching their brakes in front of you, to get attention, only gets a baleful glare from me and muttered hatred under my breath. Give me the constant hum of the motorway as opposed to a quiet street suddenly infected with souped up engines or lager louts.

Like Robert, multi-tasking panics the hell out of me, as job interviews used to as well (thank God I am retired now and can avoid that hell of "What do I say?" "What do they want from me?"). I followed Tony Buzan's methods from the Sixties, which included mind mapping and key words. I presume Word Finding is another version of this? I no longer argue with anyone and put up with the rude comments that come from more base human beings (poof and queer) as apathy keeps me out of fights with people who don't care and don't listen; in the words of a Roy Harper song, "There's nothing I could have told you that you would have understood. And there's nothing I could have told you that would have done you any good."

Seb, trying to explain things to my wife is also something I have given up on ("Too much information" was her usual response). Boring or weird occupations? "Nobody wants to read your stuff." "Why do you keep sending things to people that they don't want? — it's a waste of

money." Here my artwork and other material gets accepted as it does on one other geeky, specialist site, but nowhere else. When you say it can be a challenge living in a messy, chaotic world, I cannot help but agree again. The unstable constantly want excitement in their lives, this is why they continually change things. I want certainty, to be settled and to know what is going on around me. Like JB (ironic initials as it is also a whisky brand's name) I am back into drinking after years of not touching alcohol because we have moved and the house needs work done on it, the old printer has gone up the spout and the new one isn't working (I don't know if it is electronic items that drive me up the wall or the complex, indecipherable instructions that come with them or their make-up because they are created by complex, indecipherable human beings).

#### Tony

Symptoms list

Hypersensitivity

Hyper-awareness

Hyper-alert (panic in social situations or under any kind of pressure)

Hypertension, which includes cramping of the calf muscles and occasionally back of the thighs

Joint cracking (fingers, wrists, shoulders, neck, knees, ankles, feet, left big toe, lower spine near pelvis (kundalini?))

Twitching and stimming (itchy palms scratching)

Cold extremities (hands and feet)

Quick-healing of injuries

Sharp pain occasionally at junction of head and neck on left side (blood clot?)

Hypertension on right side of neck

Migraines (stress from sensory overload?)

Food intolerances

Indigestion

Flash of light over right eye when I have an idea or gain insight into something

Occasional bright flashes seen out of the corner of same eye

Occasional static shock problems

Can't tell right from left

Obsessive note-taker and list-maker

Socially and physically clumsy

# Pen pals

#### Pen pal number 306

Hi, I'm Catherine and I'm 44 years old. Born in Liverpool, live on the Isle of Wight. Would like to write to penpals from England or Abroad. Happily married. Write to craft penpals. Enjoy reading, writing poems and stories. Travelling, watching films, shopping, making cards, painting, glass painting, adult colouring, jewellery making. Love animals, love walking, love hamsters. Take care,

love Cathy x

#### Pen pal number 307

**Hi, I am Karlin** from Malawi; I would like to meet with new people; I am 37 years old; I like sports, swimming, cooking, gardening, watching TV, museums, and nature.

### Pen pal number 308

Hi, my name is Laura, I'm a 28-year-old with Asperger's. I am a bit of a loner and have very few friends. I have had huge social difficulties my whole life and now in adulthood I struggle to hold down any job I have, purely due to my lack of social skills. I have been bullied at many workplaces and suffer with bad anxiety as a result. I am looking to reach out to anyone who can comprehend and understand these difficulties.

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

# 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 309

Hello, my name is Paul. I was in a special-needs class at school. I am looking for a penfriend; I do acting and drama, mainly comedy, and like to make people laugh.

#### Pen pal number 310

My name is Connor, I am 14 years old and live in Surrey. I was diagnosed with autism around the age of 11.

I really struggle with making friends and often feel lonely as no one wants to meet up with me. I often feel everyone hates me, which makes me feel down.

I am trying to learn the guitar, I like music like Led Zeppelin, David Bowie, Beatles, Nirvana, and so on.

I like *Doctor Who?* and writing stories. I also like playing games like *Sims4* and *Halo* on the Xbox. I have recently been watching *Stranger things* and really enjoy it.

I'm interested in crime documentaries.

Would like to hear from anyone around the same age.

#### Pen pal number 311

My name is Salome and I am 13 years old from London. I like making animations, cooking, crafts, video games and making comics. I also love animals and birds. I am nice, friendly and kind. I sometimes feel different and find it hard to make friends.

I would like some girl pen friends around my own age to write to. I am really excited to find friends around the country who I can talk to.

#### Pen pal number 312

Hello my name is Thomas, but you can call me Tom. I live in Rutland in England.

When I was two-and-a-half years old I started showing symptoms of autism; my mum and dad had no idea what autism was. I was taken to the doctors' and when I was 5 I was diagnosed with autism.

I like cooking, history, writing stories and running. I also do karate, Scouts, Duke of Edinburgh award and park runs.

I have a pet hamster called Rover.

I am 14 years old.

#### Pen pal number 313

Hello, my name is Katy:-)

I am 18 and I was diagnosed with autism a few months ago. I would prefer a pen pal closer to my age, but I don't mind too much if we get along.

I am taking a college course in performing arts and hope to one day pursue it further.

At least half of my life has been taken up obsessing over tv shows, books, games, and music. Essentially, I'm a huge fangirl . . .

I hope to hear from you soon :-) Byeeee

#### Pen pal number 314

**Hi, I'm Sophie** I'm 32, was diagnosed 12 months ago with high-functioning autism after struggling for years to get the correct diagnosis.

I'd love to chat to others in the same situation as I'm finding I feel very isolated.

# The body keeps the score

by Bessel van der Kolk

ISBN: 978 0 141 97861 1

published by Penguin

#### review by the Goth

I am scared of reviewing *The body keeps the score*. Trigger warning: the book includes multiple case histories of all sorts of abuse, from the pettiest acts of meanness in primary school children to the most seriously traumatising road-traffic incidents and combat atrocities.

Nevertheless, I found the book immensely helpful and instructive. I think anyone who gets stressed or who suffers from anxiety could benefit from reading it, especially if they take some of the principles of treatment and apply the principles to their lives.

Van der Kolk examines the roots of longstanding anxiety, explains the physiology behind our reactions, and considers several effective ways of improving someone's coping.

Methods include psychotherapy, massage, yoga, neurofeedback, meditation, theatre workshops, community volunteering, and learning how to breathe. And each one is carefully justified; examples of the people who benefited are given. His empirical credentials are impeccable.

I have been studying psychology and psychiatry for over thirty years, and never before

have I read such a realistic book by a professional within the field — usually books like this are written by "mavericks" or unqualified outsiders, with the consequence that I don't know whether to trust them, or maybe they are more of a nutter than a maverick. No such doubts of a man with a career in treating, first, Vietnam veterans and then broadening his career to victims of rape and then traumatised children.

He never mentions treating Autistics explicitly, but from my own experience of corresponding with readers and talking to readers at various events while I have been producing the Spectrum — that's 2005-2020 (including when it was Asperger United) — I reckon that at least 30% of Autistic readers suffered major traumas. So, he almost certainly has treated many people who could get a diagnosis of Autism — studies have shown that a larger proportion of Autists have anxiety and stress disorders than is typical for the general population.

Please, read with caution, being aware how upsetting it might be, depending on your life experiences, but if you struggle with stress or anxiety I hope that this book will give you new coping strategies, encouragement, and hope for a better life.

If sufficient material is sent in, the theme for July will be uncertainty, change and how to cope (please see the editorial). 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!

# letters to the Editor

I was diagnosed in my late teens, and then a lot of things made sense. One of these things, of course, sensory sensitivity.

My mother always told me stories about how a certain blanket would sooth me to sleep, how I would cry visiting my birthfather in prison because of the echoing walls and how I would store sand in my pockets and constantly have my hands in it.

Recently, I have invested in stim toys. I looked for ASD-owned businesses and found StimSensory. I have a slow-movinggel hourglass that I was very attached to during my therapy sessions, a chewable necklace since I have a biting habit, some squishy animals and other items.

Most people would think it's childish or embarrassing to be 20 and buying toys, however, my sister is in her thirties, is neurotypical, and still buys toys for herself. *And why should it matter?* It's not hurting anyone and it's making our lives more comfortable. Sometimes I do feel weird being a full-grown goth with a plush shark and chewing on a necklace . . . but the important thing is I feel more comfortable.

So don't be afraid to be strange or weird, and invest in stim toys! They help in so many ways — bad habits, anxiety or concentration.

And don't be embarrassed to stim in public! I clap, vigorously do jazz hands, click fingers, shuffle and do my own foreign sign language. It embarrassed me for the majority of life but I had a tattoo appointment and my tattoo artist has a daughter on the spectrum and he is the most understanding and makes me feel comfortable. And he told me that life is too short and unexpected to be embarrassed of being different.

I may get that quote tattooed on me.

#### Dear Editor,

this letter is in response to Nicky's piece on *Autism* and sex in the October 2019. I was pleased to see an article addressing this. I am currently waiting for diagnosis referral and I have what others consider an unconventional attitude to sex for someone of 26. In fact I have had an abnormal relationship with sex for as long as I can remember, at least abnormal in neurotypical terms.

I have had a series of sexual relationships with people that I developed intimate relationships with, however, I did not find the sexual aspects enjoyable. Sex was something I did because I believed that was part-and-parcel of a romantic bond between people and something to be expected. To be clear, it was never non-consensual. I didn't care enough about it, or ascribe enough significance to sex for it to not be consensual. I simply went through the motions, never really understanding what it was meant to be doing for me. I, like Nicky, found it uncomfortable and confusing.

I am not sure whether this was because I found it over-stimulating, or because my body did not become aroused. The latter is likely because I never was able to get into it psychologically to trigger the correct bodily responses. It is has not been for lack of care or love for my previous partners but either way sex has felt like this odd tradition — something I have had to do out of human obligation. I just can't be bothered, and pretending it's emotionally rewarding has felt dishonest.

I now identify as asexual. I believe that my autism has strongly contributed to this detachment from sex. I now accept that I have absolutely no interest in sex and I openly share that engaging in sexual behaviour makes no sense for me. This is not something that I or any other asexual people should be ashamed of.

I hope more people provide their experiences on sex to the magazine as I think it is a worthwhile conversation that could help people to understand themselves, especially younger people who struggle to understand why they don't find sex as desirable as society suggests they should. I would be very interested to learn more perspectives from fellow autistic people.

## letters to the Editor (continued)

#### Dear Goth

This is in response to the very thought-provoking article in *the Spectrum* (October 2019), *Socialising and loneliness*. I very much hope that the author, Richard, will see this letter (your having published it in the next edition of *the Spectrum*).

What Richard has said, in his article, regarding cults, rings very true to me. And I would very much recommend his article to anyone who would like to gain some understanding of just what a cult is and what is the effect upon people who get involved with cults. From the dictionary, the definition of a cult is a "system of religious veneration and devotion directed towards a particular figure or object, such as the cult of St Olaf." Richard's description of the organisation that he became involved in accurately fits this definition. There are, in my opinion, two crucial aspects of cults that define them and which point to the problems that they cause (just as they affected Richard). These are that a) they are centred on the "cult of personality" (like the cult of personality that obtained in the Soviet Union at the time of Stalin) and b) they demand absolute and unquestioning obedience from their followers. Moreover, they invariably begin by being exceptionally attentive and friendly towards the individual who turns to them for help and support but which then, over time, become exploitative and authoritarian. And what they don't know about mind-control is not worth knowing! For it is invariably their objective to become fully in control of the mind of the member of the cult. In other words, they are geared towards indoctrination. And, in truth, they are almost always utterly ruthless in the way that they conduct themselves (although they go to very great lengths to hide this). But are cults just queer organisations that one finds out on the fringes of society? No, most certainly not! For, given the definition that I have quoted, two of the so-called Abrahamic faiths (that is, Christianity and Islam) are certainly cults, whereas the third such faith (that is, Judaism) most certainly is not!

To avoid getting enmeshed in a cult may be very difficult. And, very often, once one gets

enmeshed in a cult to a certain degree, it can be well-nigh impossible to escape. Therefore, it is much better to not allow oneself to get involved in the first place! But what to do if you do find that you have been sucked in and can't seem to be able to escape? Well, you, Goth, have given much very valuable advice on this matter in your postscript to Richard's letter. But one may find much very valuable advice as to how to escape from a cult by searching the Internet. Where there is information about bona fide organisations that provide advice and support to victims of cults and their cruel exploitation. Richard, I do very much commend you for your service to the public by drawing to our attention the dreadful danger posed by cults. Thank you very much indeed.

Yours sincerely

#### Jehovian

Jehovian's letter was received in December, after the January edition had been printed, so I was unable to include it until now.

If you are concerned that you may be involved with a cult, or if someone you love is involved with a cult, then information is available at:

#### https://cultinformation.org.uk

Some similar sites are actually run by cults and give disinformation, but this site has a good reputation.

If you are unsure if you are involved in a cult, or in any other situation where someone is coercing you, look up information on the BITE model. BITE stands for Behavioural control, Information control, Thought control and Emotional control. The BITE model was developed by Steven Hassan, who is a professional counsellor in the United States and who has written extensively on cults and mind control, including three books. Professionals (psychologists and counsellors) argue about whether the BITE model is correct, but even if it is not entirely accurate, it is useful for helping you to work out whether you are in a coercive relationship or not, and that is what is important when you are worried about your situation, Editor.

#### The Puddle Patter

#### by Moxy

I meet a Puddle Patter
And he's careful not to splatter
Any moist or muddy matter
On the pavement and my sweater.

I ask him as he huddles Why he bothers patting puddles. "Well, I used to give them cuddles But I ended up much wetter."

# The problems NTs have with us

#### by **Tony**

I hadn't thought about stimming much until today, when visiting someone. Sitting there feeling nervous, I stated licking my dry lips, twiddling my thumbs and darting my eyes all over the place, among other things. It is no wonder with this odd behaviour that we throw "normal people" and they think we are peculiar. We are strangers in a strange land, to use the book title by Robert Heinlein (probably based upon a quote in the Bible) and it shows.

#### Dear Rachel,

I have had identical and similar comments including "I wouldn't have guessed you were autistic" over the last three-to-four years since my diagnosis. These comments have come from other autistic adults as well as from very senior and experienced psychologists and psychiatrists who work in the field of diagnosis and assessment. I don't find the comment particularly stigmatising, discriminatory or pejorative (maybe I should) and therefore reply with a "Oh, that's interesting, I must be a good actor". I feel this reply reflects my diagnostic journey (having been diagnosed in my thirties) and my belief that my autistic traits are more apparent when I'm at home.

I therefore hope you find a personally meaningful approach to dealing with this situation if it arises again in the future.

#### **Patrick**

#### Dear Goth,

I found out on Tuesday, 14 January, that come October I'm going to the University of Oxford to study Chemistry! I'm both very excited and slightly worried because it's a big change. Does anyone have any tips for adjusting to university?

#### An apprehensive student

#### Dear Goth,

no, we should not conform at all as each and every time we give in to others' demands, it takes a little something of us away. I have tried this for years prior to my diagnosis and have only just realised that no matter how I try, I will not fit in. Since this time, I have made a lot of changes to my life and I am so much more happy for doing it. I now accept who I am and am proud to be different and love every minute of it. Please do not waste time trying to

conform as it will only lead to hurt and wasted years.

But I wonder if those not on the spectrum wish to conform, as most people I meet would love to escape the confines of everyday life and do something more worthwhile with their lives. Are those that conform truly happy? or does the mere thought of doing something different fill them with fear of rejection?

#### Nick

# A captive audience

#### a review of the Gerald Durrell Zoo in Jersey

#### by Virginia

As a child of the Seventies, I have vivid mixed memories of my first visit to a zoo. The zoos of my childhood were dark and dreary places; I have deeply unsettling recollections of the tiger pacing in a cramped cage, staring unhappily at my freedom. The cage's proportions were akin to Harry Potter's cupboard-under-the-stairs: the concept was like fitting it with a window and charging an exorbitant price to gawp at the inhabitant. No wonder the tiger roared! Zoos, then, for me, resembled a prison for animals. There are those who declare that zoos are not dissimilar to freak shows, in the way that they attract such voyeuristic entertainment at the expense of the animals' freedom, especially now that some intriguing cross-species have been created, such as the zeedonk, liger or tigon. Surely these freaks of "un-nature" are just aberrations?

Given my memories of the unhappy tiger, it was not surprising that I should feel reluctant to visit one again, thirty years later, whilst on holiday in Jersey, but the general consensus was that it would be a great day out to a famous zoo, so I went along with it.

Despite the slightly disturbing moment when the orangutan fell in love with me, a fellow ginger, I couldn't have been more pleasantly surprised. It seems to me that, if this was anything to go by, the zoos of my childhood, like the smelly and cruel circuses, were a thing of the past. Many of us are familiar with *My family and other animals*, either the book or the television series, and Durrell's love and respect for animals was abundantly clear in this zoo. The animals had spacious, clean habitats, tailored to their needs, and the zoo was bright, clean and friendly. The inhabitants looked happy and healthy as they roamed about; no miserable pacing up and

down. Even the shows revealed enthusiastic performances from creatures who clearly had warm relationships with their dedicated trainers.

In my teaching work, I once read an extract from Durrell to a class, where he recalls his realistic view of the animal kingdom and his philosophy behind keeping a zoo. The extract recalled an operation on a monkey to remove a parasite. He describes the procedure in gruesome detail, including his observations of his young assistant that day, a journalist, who had misgivings about animals in captivity. She had not realised how much distress was suffered from parasites, and how much less discomfort they felt in captivity, where they could be monitored. He was able to treat animals for conditions from which they would be very uncomfortable, even die. The lady acknowledged that he offered a service which was definitely in the animals' best interests. Durrell reflected that it would be wise to understand a little more about animals living in the wild before condemning those placing them in captivity.

In many ways, the zoo in Jersey resembled a wildlife park. We were able to see many animals which were in danger of extinction and could be best protected in a zoo, and we were able to get close to several of them. As for those new, crossbred species, perhaps it is a good thing to expand the animal kingdom, even if it did feel a little "manufactured"?

If you happen to visit Jersey, which is certainly a beautiful place to see, don't fail to pay the zoo a visit. If you are an animal lover, you won't be disappointed.

I recall the somewhat disturbing moment when an orangutan fell in love with me.

# My story about Anxiety

#### part one

#### by **Eva**

To anyone who I *might* share this with, I do, at the time of writing this story, suffer from anxiety. This story is based off of my interpretation of my Anxiety and as such, please don't take anything too seriously. All my thoughts, actions, and feelings in this story are mostly fiction. One event that happens (to give the story some depth) is *entirely* fiction. It was only to give Anxiety some character. Otherwise it would be a very depressing story about me feeling ill all the time. So please don't take this too seriously. I did write this happily, so don't think I wrote this depressingly! I just thought it would be interesting to give my Anxiety a slightly different character to what I've heard it being described as before.

Now, with that out of the way, I hope you enjoy my weird story I've written!:)

As I get ready for bed, I replay the school day through my head. The school day that was ruined by anxiety. I was unable to eat or drink because of little things that worried me, like what substitute teacher we were going to get for maths today, whether or not the girl I found difficult was sitting next to me in class, if the short tempered teachers were in our next classes or not? Things like that. When school finished for the day, I walked out with a headache from dehydration and an aching stomach from lack of food. And I was exhausted. And it was only Monday.

I finish brushing my teeth and walk back to my room. I get into bed and pull the covers over myself. I'm worrying about tomorrow, though luckily I'm not feeling sick, which is most of the time these days. As I lie trying to get to sleep, I remember a class from earlier: PSHE. I recalled that we were talking about mental health, since it was mental health awareness week this week. The teacher explained that Anxiety and

Depression are like invisible gremlins that sit on your shoulder and whisper things into your ear, though Depression is worse than Anxiety. Even though Anxiety is making my life miserable at the moment, I'm super glad that I don't have Depression. And I have no intention of getting it. I wonder though. The way the teacher was talking about mental health conditions almost made it seem that they were real entities with physical forms. Invisible to the rest of the world, but very real for the people who experience them. I continue to think about this concept as I slip into unconsciousness.

I blink open my eyes and immediately sense that I'm dreaming. I'm in a shady forest, but I can still see the sun peeking through the thick canopy of trees. Suddenly I see something move between the trees. The movement is too fluid to be a shadow, I think. So what could it — my thoughts shatter as I see a tall, black figure step out of the trees. It has large, unblinking, pure white eyes and is as tall as the lowest branches on the trees, which are way above my head. I notice that the being doesn't have a stable shape, the outline of its body having a continuous movement to it. I also notice the horns that protrude from its head, although instead of curving up to form a point, I saw instead that they curve downwards, but not inwards, like most. They too, had no fixed form. Its arms are long and thin, and it has clawed, shadowy hands. I take a few steps backward and its white eyes immediately rest on me. I know exactly who this entity is. It's Anxiety.

This was how I always imagined my anxiety, since everyone's anxiety is portrayed differently. It looked exactly like how I'd imagined it to look. I wondered if its personality would be any different. Most people who had experienced anxiety said it was a voice inside their head,

# a story (continued)

telling them that they were nothing, that they were weak, that they should just give up. But was that the same for everyone else?

I turn my back on Anxiety and run. I thought I could escape it by sleeping, but apparently it plagues my dreams too. I run into the trees, desperate for this dream to be over, yet dreading the next day I have to face. I pause to catch my breath and gather my thoughts (because apparently you can run out of breath in dreams). I turn around and nearly crash into the black entity, who had somehow appeared behind me. I inhale sharply and step back. Anxiety gazes down at me and without saying anything, reaches out a clawed hand towards me. "Go away," I hiss and run in the opposite direction. I felt tears prickling in my eyes (because apparently, you can also cry in dreams). I dodge around a wide tree trunk and, low and behold, Anxiety's there. Following me. Just like it does in the waking world. This continues for a few minutes, Anxiety always appearing behind or in front of me. After it blocks my path for about the fifteenth time, I break. "Just leave me alone!" "I've dealt with you all day!" "Why can't you leave me be when I sleep?!" I scream, letting the tears finally spill. "What did I ever do to deserve you?!" "You've made me feel sick with nerves, literally!" "You've made me scared of eating and drinking in case something bad happens!" I pause and I see it standing across from me and notice that it's not staring at me. It's looking at the ground, its form deforming alarmingly. I sink to the forest floor and begin to sob properly, staring hard at my lap. "The past two years have been so hard," I whimper quietly. "It's not fair."

I remain sitting on the leaves, my head bowed and my eyes closed, trying to calm myself and hopefully wake up from this nightmare. I'm like this for about a minute when I sense a certain presence in front of me. Even without opening my eyes I know it's Anxiety, probably come to laugh and say how weak I am for crying, even though I've never heard it say anything like that before. I've only felt the effects of it. But what Anxiety says next completely changes my perspective of it.

"I'm so sorry," it murmurs and I feel a hand being placed gently on my cheek. My eyes fly open. I wonder if it's just being sarcastic but then I notice it properly. Anxiety has knelt in front of me, though it still towers over me. It's almost copying my position, with its hands clasped in its lap. I look up at its face and I see sadness and sincerity there. Its eyes, though they are completely white with no pupil, look so sad and full of guilt that it's a struggle not to look away. I see the outline of its body sparking and moving in waves, making its horns look softer, even though they weren't very sharp in the first place. "I'm sorry for putting you through this horrible experience," Anxiety continues, its gaze holding mine. "I thought that I was keeping you safe, stopping you from going out by yourself, stopping you from eating, stopping you from actually enjoying yourself, but I was wrong. Very wrong." Anxiety drops its gaze in shame, its outline getting more warped as it speaks. "Instead, all that I succeeded in doing is making you unnecessarily scared, worried, and ill and for that, I deeply apologise."

I'm so taken aback by what Anxiety just said that I just stare up at it in shock. Anxiety takes my silence as a bad thing and quickly withdraws its hand. "Of course, you don't have to forgive me. You have no reason to. I'm sorry," it says in a panic and moves as if to go. I snap out of my trance and see it about to stand.

"No, don't go!" I blurt out. Anxiety freezes for a second, before sitting back down again. I meet its gaze, my eyes still slightly blurry from crying. "I always try to give people a second chance, should they mess up," I begin quietly, "and that includes entities such as yourself. So yes, I'm willing to forgive you." I give a small smile.

Immediately, Anxiety's form calms until its outline is a gentle ripple. "Thank you," it whispers.

"So, you're sure this is real?" I ask Anxiety, who has moved to sit beside me. We're now sitting underneath one of the trees.

The second and final part will appear in July.

# Acting like everyone else

#### by Kayleigh

Society makes us dress a certain way. Speak a certain way. Act a certain way. Anything that doesn't meet the society norms is supposedly cause for punishment or exile. As a woman with Autism I suppress it daily, unless you saw me comfortable at home you would never know I was on the spectrum. Which frankly is a sad reality that so many women feel like they can't be themselves and still succeed.

I don't allow myself to show my autistic traits at work even though it definitely isn't an autismfriendly place to be. I get burned out by the end of each day and no one can see it. No one can see the discomfort I get from the artificial lights, or how deafening it can get. No one understands when I have trouble concentrating and I hide my stims by bouncing my leg under the counter. They wouldn't know I break down in tears of exhaustion most nights or that it is a battle to get out of bed. I have been brought up thinking that I must conform to get by and that I don't deserve "preferential treatment" because of my difficulties. I have been told not to inform employers of my Autism because I might not get the job or that I will be first in line to be fired because I am different. I have been made to feel ashamed of who I am and how hard I find it to get through the day. Every time I tripped up and showed my authentic personality, I was bullied for it. I still am bullied by those who feel they are better and more deserving than me to work the days they want or to have extra time off. People take their anger out on me when I fight for my rights as an employee and make sure I leave work at the same time each day. People think I'm somewhat privileged to not be kept behind after work. They aren't aware of how hard I fought to have a set work pattern or how difficult it is when that routine isn't there. I have been told that I "act fine" and "don't have any issues at work" or that "people go to work with mental health issues every day and just deal with it, you shouldn't be any different".

Why should we act like everyone else when we have so many abilities that many neurotypicals don't? We can be perfectionists. We can have a great attention to detail. We can be very focused. We can be great at communicating. We can be great at dealing with difficult customers. We can be great at including everyone and treating everyone as equals. We can be great in charge and keeping things in order. We can be great at resolving conflict. But for some reason if we show our "bad" traits no one can see what we are really good at. They think we are flight risks and don't want to include us in case of a meltdown. They don't always want to hear what we find challenging especially if we don't show it. Neurotypicals that hold down a full-time job but don't enjoy their work have a very different experience than someone with Autism who finds their job distressing. I think it is important to note that a lot of people do struggle in their jobs but people with Autism should never be spoken down to or have their struggles ignored. Just because people don't like their jobs doesn't mean we struggle in the same way.

I worked forty-plus-hour weeks for three months in retail and had a breakdown. I worked indefinite thirty-five-plus-hour weeks in my next job in a busy post office and had to fight just to get one regular day off for counselling I dealt with the doubt from my managers that it was a legitimate reason for time off. I had to avoid them after my session as they seemed to think I should be there all day, otherwise I should be at work. I pushed through my ASD assessment, moved out of my parents' house and had to try and hold my life together. I spent weeks speaking to HR and the branch managers practically begging them to understand I was struggling, and that Autism is real despite the fact that they can't see it. I worked really hard to get hours that, although they are a compromise, work better for me. I fought for an extra day off in the week so I

could fit appointments alongside time to rest instead of arguing with my bosses when I needed a couple hours off.

I don't want to pretend anymore, and I want to unmask without shame. It is crazy what we have had to deal with as Autistic women. We are strong and resilient to say the least and we are allowed to have meltdowns, we are allowed to feel the things we do. We should keep fighting, not all disabilities are visible but that doesn't make them any less valid.

Women with Autism, I commend you for getting through each day and continuing to challenge the social norms! Congratulations if you stim in public or ramble about your special interest! And well done to those of you who prove we do not have to fit the stereotype neurotypicals created for us!

I have had enough of pretending to be like everyone else around me! I've had enough of trying to cope with what neurotypicals find acceptable! I have had enough of people trying to make me something I am most definitely not! You shouldn't either. It's okay to feel afraid of showing who you really are, but I hope, in time, we can all just be authentically us and there be no judgment.

I don't have any advice to give, but I hope other people can connect with my story and know they aren't alone. I have started a blog if anyone wants to connect with myself and other people with Autism on

#### kayleighcreativeworld.wordpress.com

It can be tough out there and it shouldn't be sugar coated to suit neurotypicals' pre-conceived ideas about people on the spectrum.

## We had to let them go

#### by Janine Booth

Ever wondered why only 16% of autistic adults have a full-time job?

He worked alone, not a team player Not a keeper or a stayer Didn't fit in, not really our sort Talked about boring stuff not sport We had to let him go She didn't smile, service with a frown Missed the big picture, always drilling down Flapped her hands, rocked and hummed Chewed her pen and sucked her thumb We had to let her go Profit margins were getting low We didn't want to let him go But some things we just can't afford We can't keep funding his support So we had to let him go Wasn't friendly — never spoke Lost her temper — can't take a joke Had some really weird obsession Didn't give a good impression We had to let her go She wouldn't put in the extra hours No party tricks or superpowers Too quiet — too loud — too fast — too slow Everyone said she had to go Great at the actual job, to be fair Well, yeah But we had to let them go

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# a photo of a sculpture, with note



### by **Tony**

Artrack is a workshop where people can make things, it is in the town of Gravesend in Kent. At Artrack we do painting, needlework, make models, drawing and textiles, some people like to use the computer. My favourite thing to do at Artrack is painting. Artrack is a nice place to come to make art to

put in exhibitions for people to see and buy.

Tony's artwork is a sculpture made from wooden pieces that have been glued together, I like that it is made from different shapes and colours.

Clive



# 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.





### On a beach

#### by **David**

On the beach

a boy showing off

to two dollies

stuck ice-cream cones

on his eyes

momentarily staying put

like Silicone breasts

defying the laws of gravitas.

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