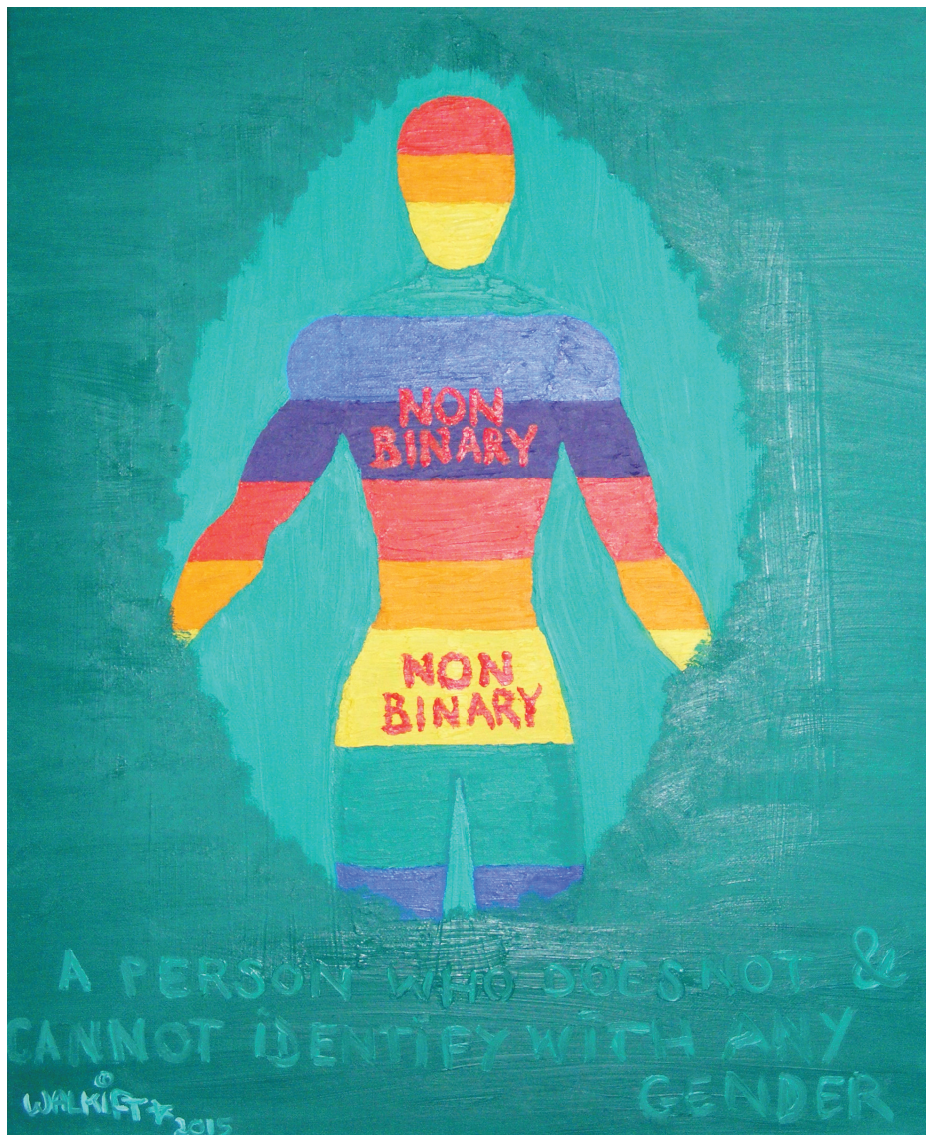


Produced by and for autistic people

The Spectrum

Edition 96 October 2018



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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:

Email: the.spectrum@nas.org.uk

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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.

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

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.

Contributions for the next issue should reach *the Spectrum* by **5 November 2018**

Welcome to the October edition of the magazine that was called *Asperger United*.

As you will have seen on the front cover, we are now called *the Spectrum*. Popular choices that didn't quite get as many votes were *Autistic Voice*, *Living on the Spectrum* and *Autism United*. These four were very clearly ahead of the other options.

As I know a lot of readers don't read this editorial, I'll be mentioning the result of the poll again on page 9, along with news of a big change to the whole of the National Autistic Society: later this year the NAS will adopt a new brand. The NAS website will start using the new brand before the January edition is out.

Lastly, it was good to see many of you again at this year's Autscope. Usually I ask a few people at Autscope to write something about the conference for the magazine, and then wait in vain for anything to arrive in my in-tray. So, a bit like buses, this year two people sent me conference reports even though I didn't ask them to while I was at Autscope. I felt I had to print them both; it is one of the most relaxing times of my entire year.

I look forward to meeting more readers next year.

Yours,

the Editor

the change edition — suggestion for next issue on page 9

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Dear Goth

I received the latest edition of what was *AU* yesterday. I was surprised and deeply disappointed at the way in which the NAS has panicked over recent “revelations” about Hans Asperger and now seeks to airbrush him from our collective history in a way that would have made Stalin proud.

In fact, the core information in Edith Sheffer’s book is not new — both Lorna Wing and Uta Frith have written on it and it is noted in Steve Silberman’s bestselling book, *Neurotribes*.

Asperger was not a member of the Nazi Party, but did benefit from being the protégé of senior colleagues who were. He was a member of a panel that approved the transfer of thirty-five children judged “incapable of educational and developmental engagement” including those with Down’s syndrome and profound mental disabilities — almost certainly including classic, or Kanner’s, autism — to Pavilion 15 at the Steinhof Psychiatric Institute in Vienna (also known as Am Spiegelgrund) where they were subsequently euthanised by starvation or fatal injection under the oversight of Asperger’s long-term colleague, Erwin Jekelius.

Today, genetic screening is available in order to give the parents of such children the option to terminate

pregnancies in cases where the fetus has a severe or life-limiting disability, and there is continued debate over questions of euthanasia and quality of life.

Had it not been for Asperger’s interest in the condition, more children with AS would have been victims of this system, and this should be an important consideration: he probably saved more lives than he was involved in taking.

There is a substantial body of evidence to show that the main reason for that interest was that Hans Asperger identified it in himself. It is inherent in the condition that our black-and-white, binary, rule-bound thinking style means that we are able to make tough decisions logically, without having them coloured by emotion. The uncomfortable truth is that in a similar situation — especially in the conditions prevailing at the time — most of us would doubtless do the same.

I am very uncomfortable with the current politically correct trend to try to rewrite history and remove all trace of historically eminent people on the basis of acts judged to be tainted by today’s standards. The Rhodes Must Fall campaign is an illustration of this, and even one of our greatest political leaders, Winston Churchill, has been targeted for such treatment. Surely it is far better to retain the statues and eponymous

medical conditions in order to remind today’s generation of the contributions as well as the all-too-human failings of yesterday’s “elites”?

There’s an old saying: those who don’t learn from history are doomed to repeat it. Churchill’s case illustrates this perfectly: one of the acts he is being castigated for is the RAF’s bombing of tribesmen in Mesopotamia — today part of Iraq. We’re currently living in interesting times with indicators that many political leaders — in particular the “populists” — have failed to heed this principle. I wonder if Donald Trump is aware of the Smoot-Hawley Act and its subsequent unintended consequences on America and the world.

Finally, with regard to people being airbrushed from history: how many of us know that the first person to write about what she described as “schizoid psychopathy” (psychopathy meaning personality disorder) in children was a Soviet psychiatrist, Grunia Sukhareva. She wrote her paper in 1925 — nearly twenty years before Kanner and Asperger wrote theirs! If the NAS is determined to rewrite history, at least do it properly and give her the recognition she deserves with a rebrand of AS as Sukhareva’s syndrome.

My suggestions for a new name — if we really have to have one — are:

Spectrum United
On the Spectrum
Different is Cool
Autistic United — this has the benefit that its
short form remains AU!

Keep up the good work!

Yours sincerely,

Neil

Dear Goth, at “the magazine formerly known as *Asperger United*”, under the current title of *The name of this magazine is going to change* (edition 95 – July 2018),

I am writing after receiving edition 95 yesterday.

I understand that the name of the magazine is to be changed, and that suggestions from readers are welcome, and that voting will be on the *AU* online page.

I read Mrs Anna Kaczynski’s article on page 5. I met her at an autism conference in London once. I think I was exhibiting some artwork there. She told me then that she was the person (then Anna Cohen) who had conceived of the name of *Asperger United*. She seemed quite a

genuine person and I do believe her heart was in the right place.

I have difficulty reading people, and probably even more reading, or predicting, future events, and this puts us where we are now, a name change (a bit like Anna Cohen, same person, different name).

Change is unsettling, but when life may give you lemons, one can choose to make lemonade (that is, change it into a good thing).

I take note of what some think of the alternative term “high-functioning autism” and also the suggestion “Highfa United”.

For myself, in seeking a new name I would revert to default settings, reboot. The original term is “autism” (self-ism). However, this name is most probably already taken, in use. So I would suggest “Autismo” (a bit like *Cosmo*, which was short for the very successful *Cosmopolitan* magazine).

Unfortunately, I would be unable to vote myself, as I have never owned a computer and am largely “computer illiterate”. However, I do hope you will accept my suggestion for the choosing by computer-literate others.

Best wishes,

Peter

Hi Goth,

the latest edition of the magazine arrived today and I see you are looking for a new name for it. Might I suggest either *Life on the Spectrum* or simply *Spectrum Life*.

Lisa

PS. This summer I am working cleaning caravans at a holiday park and am finding it very compatible with my AS (or whatever it is going to be called in the future — Kanner’s syndrome?)

as it is quiet, routine and I am left alone to get on with the work at my own speed and in my own way so long as I get the vans I have been allocated done in the time allowed. Maybe others on the spectrum might like to consider such a job even if it is well below their intellectual capacity.

Unfortunately, Life on the Spectrum is a UK charity and Spectrum Life is an online magazine, so I couldn’t allow either of these names into the poll. Several other suggestions had to be excluded for these sorts of reasons — names already in use elsewhere, Editor.

two more featured letters and a filler

Hi Goth and AU readers,

thanks so much for including my article on pages 10 and 11 of edition 95 of AU. And the poem by Alain on page 6, *'Tis better*, is brilliant. I also enjoyed seeing pen-pal adverts for a couple of people I am already penfriends with. I wish them every success.

I have to admit it really knocked the stuffing out of me to read that *Asperger United* won't be called that any more. But I totally agree with the decision to change it. I'd really built up an image based on Asperger's syndrome. If I tell people I'm autistic I fear they might not believe me as I am very "high-functioning", or at least in the sense I can hold a conversation, show interest in others and read some, at least, body language. I am a bit eccentric though. But yes, not everybody likes the term HFA or high-functioning autism, I presume because if someone sees somebody as high-functioning, they may think that there isn't as much of a problem. Whereas I know from experience that there is. I was very shy at school and college, especially in a class setting. It racked me with anxiety going to school, being with the other kids. But not feeling like them.

I was wondering how it came to light about the wicked things Hans Asperger did? I wasn't aware of it until a friend told me about it a couple of months ago. Now I come to think about it, it is surprising that this hasn't been researched before. I might be showing my ignorance there, sorry as it might have been. But I was unaware of it.

On a happier note, I really enjoyed the last edition of *AU*. What sticks in my mind are the poems. I love to share my poetry with people so I might send some in soon. The poem on page 15, *Footnote*, is very clever. And *The temple* on page 18 I like too. I might research Hermione Cameron's poems. So a big thank-you to her.

As for a new name to replace *Asperger United*, I tried brainstorming some ideas. The best I could think of was "Aut-ternative Universe". I chose this title because I like the wordplay on alternative universe, and it has the Aut bit in short for autism. Also, ours can be a different world. I often feel that I live an alternative existence to others and I'm not quite like others. Hope that idea doesn't sound too silly.

Love,

Daniel

Please see Neil's letter about the history of Hans Asperger, Editor.

Dear Goth,

firstly I hope that this letter finds you safe and well just as it left me.

I must say I was shocked to learn that *AU* is changing its name; I do understand why because of the new information that's come to light about Hans Asperger himself. I think it's great that we aren't linked to him in any way because of his cruel, sadistic, callous and inhumane acts.

I completely agree with what Anna says on page 5 of edition 95: we as people with Asperger's don't want to associate ourselves with his name and have fears of repercussions because of that.

I whole-heartedly agree with the name change and like Anna's suggestion of *Aspies United*, but like you am really not comfortable with "Highfa".

Thank you,

Matt

We destroy things around us to simplify our lives, when we can't deal with new input and build upon them in those areas where we shine (flower in our strengths or complicate our lives with detail).

by **Tony**

Pen pals

Pen pal number 270

Dear *Asperger United*,

I name is Darryl. I like put ad in pen pals in your magazine. I am 47 with Asperger's syndrome. I like music, Seventies, Eighties, Nineties, all pop music. I like Eagle Radio. I love to hear from people have same problems as me.

Thank you,

Darryl

As this was the only pen-pal advert received this quarter, to fill the page, here's a poem, Editor.

Always, always do

I tried to keep it a secret.
But I couldn't keep it from you.
You knew just how to reach it.
You always, always do.

You disarmed me with your charm.
I wanted to hug you.
You sheltered me from harm.
You always, always do.

The atmosphere was electric.
A current around you.
You love and protect me.
You always, always do.

by Daniel

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 / this magazine cannot intervene or be held responsible for any ensuing correspondence between letter-writers.

an article, with an accompanying letter

Dear Sir/Madam,

my name is Yasmin and I am 15 years old. I contacted the National Autistic Society today and previously sent an email via *Asperger United*.

I am in the process of being home-educated and I have a diagnosis of high-functioning Asperger syndrome. I was diagnosed at the age of 7.

I have a passion for journalism specifically, and writing in general. I am also the published author of *The way I see the world*, which is a collection of poetry (currently available on Amazon). My poems are written from a perspective of living with autism from the inside out, on a daily basis.

My ultimate goal is to raise awareness for people with autism and Asperger's, through my passion for writing and communication. Additionally, I have also written and presented a public speech for One Voice (a parent support group for parents of children with autism and Asperger's) on the subject of living with autism on a daily basis.

My main objective is to enter journalism as a career and to continue with creative writing.

I wondered if you might be interested in my latest article: *Time for change?*

I would greatly appreciate it if you would read through my article and either provide me with your comments and suggestions and possibly consider it for publication.

I would also like to ask whether you may offer young intern schemes or courses you may run for potential journalists.

I would really like your feedback.

Yours Faithfully,

Yasmin

This magazine is a very small affair, needing my time just one day a week, and I write very little for it — it is written by you, the readers — so I could do with a deputy to help with editing and admin, but not journalism, sorry, Editor.

Time for change?

by **Yasmin**

Michael Landon. Melissa Gilbert. Melissa Sue Anderson. Sound familiar? *Little house on the prairie* was an American drama series set in the late 1800s. The show is based on the best-selling series of Little House books by Laura Ingalls Wilder. The series depicts a moralistic family, who live on a small prairie farm, situated on the plains of Walnut Grove, Minnesota.

Nowadays, many movies and television programmes represent the subjects of killing, drugs, sex and whatnot. Where have the fun, family-orientated, moralistic movies gone to? Why have they disappeared?

Perhaps they are new to the eye, enticing and a way to escape the supposedly “boring” everyday values we were once taught. Once upon a time, we lived in a world full of true values. Every child was taught the importance of respect, privacy, being kind to others and to not say or do anything that might cause harm to the world or our fellow neighbours . . . and if you did anything of the sort, you were in for it!

Sadly, today with the world changing so robotically, children are being taught quite the opposite of those true values. Whether it's being exposed to an increasingly popular trend for

an article (continued) and two notices

bloodsucking vampires (of the “romantic” kind of course) or having a sneak peek at an erotic love film on the TV, or even having a sex toy pop up on your TV screen, children are learning that if you are not happy with the way your life has turned out, fantasy can dangerously be transformed into reality.

Surely, this places a huge amount of pressure on young, innocent minds. I am certainly not being a prude here — but I am just concerned about how we are seemingly corrupting the minds of our future generation, by filling them with images that they don’t need at such a young age.

Now! You may be asking how that is possible because movies and TV programmes are just a source of entertainment. *Right?* Well that may be true. They want an escape route

from the pressures of exams, peer pressure and detentions. So, they are roped into believing that sexual relationships or drugs at a young age are desirable. Why can’t those same events make their lives happier? This is what the media is encouraging them to think.

Don’t call me old-fashioned, but I really do believe that movies like *Little house on the prairie* and *The Waltons* are full of wholesome family values, with no vampires in sight! Their lives are a far cry from the aggressive and often overwhelming depictions of the lives portrayed in movies today. They display love, warmth and loyalty.

Something has got to be done to reintroduce the old values into our daily lives. It’s time we started a new chapter in the great book of life.

Changes at the National Autistic Society and *the Spectrum*

by the Goth

Another change is coming, which affects the whole of the National Autistic Society. After several years of deliberation, the NAS has decided to adopt a new brand, so you’ll get to see the new logo on the January edition of *the Spectrum*. The “loop”, the line that appears near the bottom edge of the cover and then runs, rather illogically, across the top of all the internal pages, will also disappear from January.

I hope you will like the new appearance. If you check the NAS website you will be able to see

the new logo, along with the other changes to the brand, such as a new NAS mission statement and different typefaces.

As you will have seen on the front cover, we are now called *the Spectrum*. *The Spectrum* got 19% of 1,600 votes. Popular choices that didn’t quite get as many votes were *Autistic Voice* (14% of the votes), *Living on the Spectrum* (13% of the votes) and *Autism United* (12% of the votes). These four were very clearly ahead of the other ten options. Over 200 different names had been suggested.

If sufficient material is sent in, the theme for January will be **the changes happening to this magazine or pets and other animals**. 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 (though I hope the subjects of change and pets will produce lots of emails and letters) 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

Dear Goth,

I loved the April issue of *Asperger United*. The albino snake on the cover is beautiful. I've never seen a snow-white snake before! Stunning!

I'm writing to you in the hope that you'll pass this letter on to the Aspie who wrote the article on page 18: *Adulthood — childhood*. My heart went out to them. As an Aspie myself with certain sensitivities and a childlike spirit I understand completely. I'm 48 and work as housekeeper to my parish priest in an environment which is peaceful, calm and non-aggressive. I'm fortunate as I too struggled with being "adult" before I had my Aspie diagnosis three years ago. I found comfort in relating to Saint Thérèse of Lisieux, the "Little Flower" who lived in a protective environment of her family, then with the Carmelite nuns. Her life story, *The story of a soul*, led me to wonder if she may have been Aspie too? I had a vocation to be a nun, but after three years realised I was too sensitive and individualistic to live with twenty other women 24/7. I've always been happy to be alone and enjoy simple pleasures. I have my own home and car, I go to Mass each day and enjoy seeing my friends — one or two at a time. I am happiest on my own with my garden plants, flowers, pretty things and in

my little "nest". I love doing craft things, too — especially making home-made gifts for the Carmelite nuns. I have a variety of what would be considered toys: sensory rubbery "squidgies" which I keep in an inflatable "puffy nest". I have always had a passion for puff sleeves. I make my own. The bigger and puffier the better. I realise since my Aspie diagnosis that my liking for anything puffy — balloons, puff sleeves, squidgies — is a special interest and is okay. Puffy things make the world alright for me. I like things that are for children, too. I think Aspies have sensitive souls. I have an Aspie friend (recently diagnosed) in his sixties. He's very dear to me and I write funny stories which he loves. He's a very gifted church organist, but is shy and sensitive and quite childlike too. We love each other like family — nothing sexual and his wife is lovely too. I think we Aspies have more fun than many "boring (neurotypical) adults".

Heidi

PS. My other special interest is in the history and spirituality of the Carmelite Order. I have done a number of translations of biographies of lesser-known Carmelite nuns and friars, into English, which are now archived within the Order's libraries!

PPS. Oh, and pipe organs!

Hi Goth and AU readers,

I'm including with this letter three poems, *Always, always do*, *Scared little boy*, and *I am broken*. You are welcome to share them in *Asperger United*. I would love that. They are actually poems I planned to read at a Leeds Asperger's Adults fifteen-year anniversary event, which in the beginning was called something like Leeds Asperger's Network. As it turned out, the fifteen-year anniversary event got cancelled because they were going to be showing football in the pub where it was to be held. I was wondering if any of your readers were at that first meeting? It was in Leeds Civic Hall, 17 June, 2003.

Anyway, back to these three poems. *Always, always do* has been published in a book of poems by Forward Poetry. It's quite musical, I think.

Scared little boy: this nearly made my girlfriend cry when I read it to her. It makes me think of the secrets I have kept in the past, like at college I was very socially anxious. But I would hide it with humour and behaving in an overly happy way. It's twenty-four years this year since I left college. And in some ways I probably haven't moved on with my life. It's difficult to be real, to be my true self. Not always, but like when I'm in shops I try to act normal when a part of me wants to say, "How are you?" I want to connect with people. Luckily there are a couple of shops near where I live and they accept me and my poetry. I have shared it with them and their customers.

letter to the Editor (continued), and an article

I find I'm happiest when I free myself to give poetry and do kind things for people. The shops that have let me have my poetry in to give to their customers, I have done those shops a thank-you card and bought them a small box of biscuits each.

I am broken: this is another poem about secrets. I feel very few people know me completely. I have a lot of OCD. My close friends, my dad, my mum, and girlfriend know most about this. I feel bad on and off, sometimes I feel a need to talk about these things. I even wondered at one stage if I really fancied my girlfriend. I felt bad because it wasn't love at first sight or an instant attraction. I felt bad because of this. But don't feel bad for me.

I think my girlfriend's gorgeous. It's just I have a lot of mental-health problems and I fear/feel that I hold her back and that maybe she could do better. We both don't have a lot of experience with love. And I suppose I feel ashamed of myself because I probably don't act or feel like other 43-year-old men. Also, sometimes I feel like I'm acting, not in the moment. But when I look back on things I'm not sure I was acting.

Thanks so much for listening to me. I tried to be as honest as I can because I feel that honesty is what will ultimately get me back on track. That honesty and love will make me better.

Love,

Daniel

I am broken

I open my closet.
Can't find my clothes.
Take out the skeletons.
And the bare bones.
They tell me secrets.
I'd tried to forget.
I see every fragment.
Through tears of regret.
I hold my skull.
It feels numb.
It shouldn't feel.
Thought life was done.
But there it is.
Its eyes are open.
Speaks my secrets.
And I am broken.

by **Daniel**

Brains of jazz and classical musicians work differently, study reveals — Classic FM

by **Heidi**

www.classicfm.com/music-news/jazz-classical-musicians-brains/

This is an interesting study. My awesome Aspie friend Michael (FRCO) is a top-of-the-league classical organist, harpsichordist and pianist. He could improvise and play jazz if he really had to but it isn't his cup of tea, for the reasons laid out

in this study. His brain is very structured and logical which makes him the perfect classical musician. I would be interested to know whether other musical Aspies are jazz or classical pianists.

Autscape 2018

My experiences

by **Laura**

I recently returned home after attending Autscape 2018. Autscape, for anyone who has never heard of it before, is a conference which is organised by and for autistic people. It is held each year and lasts for three days, and the programme includes a range of talks, workshops, discussions and leisure activities. Each year there is a different theme — this year's theme was *Exploring inclusion*.

This was my third time at Autscape — so far I have attended in 2016, 2017 and 2018 — and I have thoroughly enjoyed it each time. The programme this year was really good, with lots of different lectures and other activities. My favourite lecture this year was Nat Titman's *The elephant in the room* — the concepts behind the talk were well thought out, it was very well presented by Nat and the accompanying illustrations were great! I also really enjoyed several of the discussion groups, which were organised and led by some of the conference attendees.

One of the things I most enjoy about Autscape is the chance to meet lots of new people and share experiences, knowledge, skills and thoughts

on a wide range of topics, ranging from autism to rugby to cats! Being around people with whom I have so many shared experiences and a similar way of seeing the world is very different to my day-to-day life, and it always makes me happy to be part of the wider autistic community and to be able to meet people who understand what it's like being autistic. Finding out that I am not the only person who experiences, thinks or feels certain things has made a big difference to my self-esteem and wellbeing. It's also very interesting to hear what other people are involved with, as many of the attendees are involved in various autism-related projects, including training, research, peer-to-peer support groups and activism.

Meeting new people can be difficult, especially when you're somewhere unfamiliar and out of your usual routine, but the Autscape organisers and attendees definitely tried to make it as easy and enjoyable as possible for everyone to get involved with different activities and to meet new people. There are always organisers around to help and answer people's questions, and the programme is designed to

ensure that there are a wide range of things to do. As well as lectures, workshops and discussions there were also "home groups", which gave attendees the chance to meet and get to know a small group of people in a semi-structured situation. And there were plenty of leisure activities available, which included piano and organ recitals, a choral workshop, an entertainment evening, quizzes, walks around the local area, swimming at the local (unheated!) lido, geocaching and various sports sessions.

Some people don't seem to go to any of the organised activities, but play with the sensory toys — there's a sensory room every year — do jigsaws or play board games. Everyone does what they like in a safe, supportive atmosphere.

I didn't take part in as many activities as I'd hoped — mostly because I was a bit poorly and really tired, and kept going back to my room for naps! — but I enjoyed the things that I did take part in. And there's always next year, because I will definitely be attending Autscape again in the future!

My life as I see it through a different lens

by Siobhan

I always felt different; I lived in my own world practically all time. I didn't actually play with toys, although I had a dolly with me all the time. My friends were child models in the catalogues: I would invent imaginary worlds with these people. Where we first lived in Liverpool, I hardly had any friends. The kids in the street just used me and called me "mong" or "spaz". I developed an obsession with mermaids: if I saw one on the telly I wouldn't be able to take my eyes off it. My dad bought mermaid statues that I still have. Even now I get that excited nervous feeling when I see a mermaid. They frighten me but at the same time fascinate me. I have always had a phobia of plastic spiders, which comes from my cousins terrorising me with them when I was small. I have a very peculiar — I don't know whether you would call it phobia — fear of religious ornaments, whether it be a statue of the Virgin Mary or a crucifix. In the room or on the telly, I literally feel sick, to the point of retching. I strongly feel this is from going to my Nanny's house (my dad's parents). Nanny had a lot of holy ornaments displayed, as my dad's family are Catholics. Mum's have never been religious.

My mum's dad used to twist my ears. This was a horrible, distressing feeling. He did it to everyone in the family, but as I got older he no longer did it. I have never liked being touched: whenever a family friend would pull my hair I'd be reduced to tears. Even if they were messing about, it would cause great distress. I remember being in my dad's friend's pub and the locals doing it to me: I always had trouble getting onto jokes. If somebody said something to me and pointed at me, I would take it personally. I would often be upset, and Mum and Dad would say "it was a joke", "this is you this is", which made me feel awful, but I don't want to blame anyone.

A lot of school is completely a blank to me, but the memories of the teacher reducing me to

tears are very clear. I remember all the pupils staring at me as the teacher shouted at me because I couldn't do the sums. I remember her pointing to her head and saying, "You've got no brain." I felt so humiliated. I don't remember telling Mum about it, but apparently I said, "Why can't I learn?" but I do remember Mum coming into the class and speaking to the teacher. I don't know what she said to her, but the teacher looked shocked. A few weeks later we looked around another school, which a teacher friend of Mum's recommended. The pupils could wear what they liked, and you called the teacher by their first name. The headmaster was a lovely man, and I found I liked the school. So I started at the school a week later. The children again used me, and made fun of things I said: one girl would invite me round to her house for tea, then the next day be horrible to me in front of the other kids. I remember her mum saying to me, "We thought you were a bit weird."

The teachers at the school let me do my own thing, whether that be writing a story or drawing a picture of a mermaid. I didn't do any of the work the other pupils did. I remember I went through a phase of spreading glue on a piece of paper, and making a picture of it by adding sand. The sand would stick to the glue, and once I had removed the loose sand, I'd have a picture of a mermaid or a pattern.

When I was coming to the end of my time at that school, the headmaster was concerned about me, as it was obvious I was having problems, and he was concerned that I wouldn't be able to cope in a mainstream school. So my mum and he decided to have me assessed by an educational psychologist. I was diagnosed with Asperger syndrome at 10 years old, and also as having some additional learning difficulties. It was decided that I would finish my school career in a special-needs school. Going to a school with

an article (continued)

children with similar difficulties was a breath of fresh air: finally I had friends. My difficulty with maths was highlighted on a regular basis: if I answered a question wrongly or was confused the teacher would laugh in my face. This made me feel small and worthless. The deputy head was an utter monster. If she asked you to get something that was across the room, she would shout at you if you went to the wrong place. She did this to me on several occasions, and my self-confidence went downhill. The art teacher was just as bad, he would shout at you and was equally impatient. This was odd, as the first year I was there he was lovely, but the year afterwards he suddenly turned, like a Jekyll and Hyde character. He suddenly shouted at our class for no reason. I remember him once laughing at a drawing I'd done — I can't remember now what it was about. We used to do woodwork with him as well, which made me very nervous. Because I was always frightened using the saw, most of the time the teacher had to take over as my hands were shaking that bad. He had an assistant with him, an older man, who was naughty. I remember telling him that I couldn't tell the time, and his reply was, "How old are you?" "Thirteen", I replied. And he said to me, "You're thirteen and you can't even tell the time." That comment made me unhappy. For all the school's faults, it was in some ways sensitive towards me. Like standing up in assembly to receive a certificate was incredibly frightening, and it caused me great anxiety, so I always received certificates in private. For all the bad times at school, there were some fun times. Like when we went to the Liverpool museum, to the Anglican cathedral, and Chester.

At home I have some smashing memories of my dad playing his records: Mum and Dad exposed me to some fantastic music. Little Feat, Marvin Gaye, Stevie Wonder, and Frank Zappa. I have great memories of Mum and Dad's friends coming on a Sunday, and Dad cooking one of his delicious curries. Dad would always play his LPs loudly, which was upsetting for me as I'm sensitive to noise. But as Dad got to understand my Asperger's more, the music got turned low. Dad had hundreds of LPs, and I remember how he used to flick through them whilst deciding

what to put on. I used to sit in the back room where the LPs were stored, listening to Little Feat and Fleetwood Mac, which was utter bliss.

At 16 I started a new course. We had four tutors for the subjects we did. Two of the tutors I couldn't take to: one was our team leader. She was quite brusque and cold: I remember when we had to practise for a presentation about our communication skills, her saying to me, "You haven't had a go at doing your presentation in front of the group, you can't get away with it." This made me feel awful as I wasn't avoiding doing it, I had been off with a heavy cold when the group was practising. When I did my presentation I talked about knitting, the different types of knitting you can do.

The other tutor I couldn't take to was very abrupt: as part of the course our group had to run our own café. Dealing with the public (the other students) was extremely stressful. I remember the tutor sent me to the canteen for sugar: I felt uncomfortable doing this as it meant dealing with a stranger. Another girl on the course said she'd ask for me, but the tutor said in an abrupt voice, "No, she has to do it; she's got to learn." Luckily when our group had to do a Christmas fair, my mum helped me run a craft stall. The parents were invited to help, and I virtually stood behind Mum all the time — because I was so overwhelmed. Those sorts of experience came back to haunt me years later, as I saw the tutor in the supermarket — I dodged out of the way. Mum and I were also in a lift with her two years ago, whilst enrolling on a college course. I felt sick: luckily she didn't recognise me. One of these tutors now is in charge of support for students with Asperger's — I know this as I saw their name on a leaflet advertising the college's Additional Support Team. I find this utterly sickening.

I did a floristry course the year after, which I enjoyed a great deal. I had a lovely support worker who I'm still in touch with. Sadly, I had to leave, as I couldn't cope dealing with customers in the florist's I did my work experience at. It was a shame, but there wasn't a way around it. To get my floristry qualification, I had to deal with

the public in a florist's. I felt relieved leaving the course, but my family felt sad and angry that the college had discriminated against me.

The first time, I went to Paris with Mum, Dad, and Eve. We had a smashing time: Mum, Eve and I leered at the waiters in the Wepler. Dad said to us, "Will you three stop staring at waiters' arses." The Wepler is a famous restaurant where all the French politicians dine. We had fruits de mer, along with steak and pomme frites. I loved the bistros where I had mussels and chips, and the French bread is the best I've had. I loved watching the world go by in the cafés, I loved walking down the cobbled streets of a nighttime. Mum and I always say, if we won the lottery, we'd definitely live in Paris. The second time we went we had a great time, we went up the steps of Sacré Cœur, her partner had to fight off all the attention Eve was getting from the Parisian men.

People coming to stay at our house, whether they be German musicians from my dad's band or friends of my parents who they hadn't seen for years, caused me great distress. I didn't know how to cope; I felt terrified at the thought of them speaking to me. Mum and Dad try their best to make people aware of my Asperger's. We don't have people staying anymore as we now live in a flat. Mum and Dad understand that it helps me to cope better when others are aware that I'm autistic. Also I've been in situations in my life when a stranger has been jokey and sarcastic with me, and I've felt very vulnerable. I'm still like that, and Mum always says, "My daughter is autistic", and it's then that people shut up.

From when I was 19, Mum was in and out of hospital. What started as a two- or three-week stay turned into a few years of Mum getting infections. Being separated from Mum was awful, and it was made worse when a man was making comments to my brothers in the hospital. I remember wanting to cry when I heard him say, "You'd think the girls would have bought your mum some magazines." Then, "You should have one of them washing, and one of them drying." My brothers found this funny, but I didn't, as the man's face was so straight. Sadly, his wife, who is

my mum's friend, was oblivious to this but could see that I was upset. I didn't feel able to tell her, so I lied and said I was worried about Mum. On another occasion a family friend came round and complained at me that our drains needed sorting out. I took this literally, and felt it was my responsibility. My mum said that it wasn't, and that my sister's partner would sort it — I was so distressed as I couldn't ignore his remarks.

During my mum's time in hospital the same friend came round to our house and complained that there wasn't any food. As I was waiting for my brother to take me shopping this caused me great distress. Another family friend was looking at our roof and said, "I'd have you up there but you're bone idle." I took that literally, and was upset. He didn't know how to deal with me, making inopportune comments to me that would cause me anxiety. After that I began a long spell of depression, where I would be happy one minute and tearful the next. It was like a black hole I couldn't get out of. I started to obsess about these people who had upset me, and it built up to a frightening anxiety.

Through therapy I have come to understand that others have always expected more of me than I am capable of. Their expectations have caused anxiety, because it has been things that I am fearful of doing. This comes from school, and the teachers expecting me to know the answers to maths questions that I could not answer.

The therapist encouraged me to write poems and short stories of my distressing experiences, but also stories and poems about my family and how we interact with one another. I hope that my life experiences can be of help to other Asperger's syndrome sufferers. I don't want to sound bitter and angry against others, I think it was a case of people not understanding my Asperger's and how it affects me. Their desperation has been to treat me normally, but by doing that they have caused me upset, and have made me feel inadequate and inferior. My mum continues to be my supporter. Because she lives with me day to day she understands me. I love her with all my heart, as I do my brothers, sister and dad.

The fourteenth Autscope

by Bruce the Wizard

It's Saturday, and yesterday (Friday the 31 August) I came back from Tonbridge School in Kent with my mum all the way back home! Mum was exhausted. She is still sleeping off the long journey home — we went through the Dartford Tunnel and everything!

Tonbridge Boys' School was like Eton for me (it is for posh rich boys) but we went for a four-day Autscope conference. There were lectures and you could pick and choose where you wanted to go. Mum and me stayed for four days — Tuesday till Friday afternoon. Mum gave the Autscope 80% marks. I saw it more as 75-and-a-half per cent. I felt a little disappointed with the lectures on offer — too many were either gender-related or impersonal. They had also moved the discussion time (after the lectures) to another time, which was tiresome, as you never knew exactly which room they were to be held in. As well as this you couldn't mix with other people from other dormitories (unlike the Yorkshire Autscope). However, I really enjoyed it (I even made a few new friends) and was sorry to come back home again.

The Tonbridge School had a lot of wildlife. I saw a red squirrel dash under the hedge

in the morning when I got up in the morning.

The school was like Hogwarts in Harry Potter and they treated us like kings . . . we even had a nice room with separate beds — but the beds were only singles and for the first night Mum and me couldn't sleep a wink. But the bathroom was okay — loads of sinks!

Took me a while to get about the place. Most of the lectures were in Big School (the assembly room of the school). There was also a Cawthorne lecture room and lots of smaller class rooms (in the opposite building).

On my first day I went to the trans group (and made a complete dick of myself) and got told to leave. Tried explaining myself to the Goth (who was there) and just succeeded in annoying this big guy. Anyway, firstly I thought the trans group was open to everybody (when in fact it was a closed group) and secondly, I class myself as transitional Asperger's (not in a sexual way) but because I got a thing about being like Doctor Who (somewhere around Patrick Troughton and Jon Pertwee's Doctor Who). Basically I hate everything about being working class and working-

class life like Count Dracula hates mirrors. I can't work as a real Doctor, in fact I can't work at all, but I got a thing about being a Doctor, on the inside. (A bit like a hermit who can't be who he wants to be within society, so he does so within himself.) However, the trans group at the Autscope conference meant something entirely different. Something about people changing their sexual gender. I hope that clears matters up.

Some lectures were extremely good, like the lecture on Asperger's and old age (entitled *Why do we disappear as we grow older?*) by Cos Michael. And I liked *The elephant in the room* by Nat Titman. Although the Thursday swimming time (supposed to be 3:00) turned out to be 3:30 and clashed with the *Elephant in the room* discussion group — again, Mum and me missed most of that!

Others, like *Exploring the art of stimming* (nobody could hear a word the guy was saying) in Big School — I thought stimming had something to do with a 2000AD comic story — and Larry Arnold's lecture on *Exclusive inclusion* wound me up a bit — all these labels, especially class (which I psychotically hate anyway). I thought everybody would turn

on each other, so I felt I had to leave the room . . .

Other lectures I found more welcoming, like the Wednesday lecture on *Untangling the knots of neuroqueer intersectionality* – Olivia Pountney (although she got ever so nervous) and my mum suggested we all sit in a big circle to help her out.

I liked the sensory room and the Lowry room (full of stickers, relaxation board games and those magnetic toy things). Didn't fancy going to lectures all the time.

Mum enjoyed the organ recital (and it was quite funny to watch Larry Arnold dance in his bare feet in the chapel). I preferred swimming (although somebody pinched my towel — I'm pretty sure it was Larry! I don't mind that — but I might put a rubber rat in his bag next year to give him a scare).

Didn't go to the yoga and meditation groups and Mum and me didn't like the film — was it *Mozart and the whale?* — made us Asperger's look like complete wazzocks — and the ending was predictable with a bubblegum relationship. However, Mum and me loved the hologram machine behind the barroom.

Didn't go to the speed dating either (I don't see how Asperger people can make relationships?). Love — that's illogical, darling.

Best of all was the talent night, with playing and singing and I met a few old friends like Larry Arnold who was playing a flute. Mum played a piano piece which went down well. The only thing that spoiled it was that it was too long — and people wanted the bar. But I went back to it to see the rest of the talent acts and everybody got some chocolates on the way out!

Bruce, first, you absolutely did not annoy me. You gave me a lot to think about, and I struggle with the noise, light and overload. I hope to run a discussion of gender roles and other societal roles at the next Autscape, and I hope you will speak to the group.

The programme stated that the trans group was a safe space for people who weren't 100% male or 100% female, so I think that would be why you were asked to leave. I am sure you did not make a dick of yourself in anybody's eyes except your own. Please don't be so hard on yourself. I know it is difficult when one's confidence is low — I'm sure many autistic people have had times when they felt everything they did was wrong in other people's eyes, but it is not true, it is just self-doubt, the Editor, the Goth.

Scared little boy

You can see it's fake.
I tried to be real.
But lies got in the way.
I couldn't share what I feel.

You saw right through me.
I didn't seem so brave.
If truth was the key.
I was locked up most days.

One day you caught me.
I was unaware.
I didn't have my face on.
Or that confident air.

You saw me sad.
Tears in my eyes.
I just wanted you to like me.
And not be some sad, lonely guy.

You saw me broken.
I was in despair.
So used to acting.
Not being all there.

I tried to hide.
This scared little boy.
I cried and cried.
For my broken toys.
Old memories flooding back.
And I couldn't stop them.
Or let go of the past.

by Daniel

an extract from a story

Hello, Goth, here is an extract from my story. I hope that gives you a little insight into the world that I have written about.

Chapter five:

The Princess of Friendship

by **Charlie**

Equestria, Ponyville, the Castle of Friendship, Twilight Sparkle, the Princess of Friendship, the Believers of Equestria, and Starlight Glimmer are all individually

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Eddie and Paul had arrived in Equestria and found themselves at Ponyville. The portal disappeared behind them. Maybe that means they can't go back to their world. Eddie had a weird feeling in his body. Maybe is because Equestria feels different to him.

Eddie and Paul went to the Castle of Friendship and ventured inside. They met Twilight Sparkle, the Princess of Friendship. Twilight was excited to meet the Believers of Equestria and she gave Paul a magic book. As Paul opened the book, they were moving pictures of Twilight and her friends in their previous adventures. Twilight asked Paul to take good care of her book. Paul said he will.

As Twilight showed the whole castle to the boys, they met Twilight's star pupil, Starlight Glimmer. Eddie was surprised to see her in person and Paul knew his friend couldn't resist her. Eddie bet that Starlight couldn't do magic. Starlight liked it when Eddie challenged her. Twilight interrupted their conversation and told them there's no time for challenges today. Starlight went to her room and said to Eddie she will see him again in the morning.

Twilight explained that her world is about friendship and it will last forever. Eddie and Paul already knew, but they loved hearing it from Twilight. Twilight said her assistant, Spike will take the boys to their room while she writes letters to her friends, telling them to be at her castle in the morning.



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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Kiss me first

by **Lottie Moggach**

Picador

ISBN: 978 1 44723 320 6

£8.99

review by **Matt**

“Where have I heard this name before?” you may ask. Well, *Kiss me first* was a six-week series on Channel 4 not so long ago — this is why I decided to read the book, to tally it up with the TV show.

The book had me gripped

from the get-go and I finished it within forty-eight hours!

Lottie has a unique style of writing that enables her to capture you and draw you in!

I think that this is the first novel about how the

Internet has really become a fixture in our lives, what it means and how it can and has fundamentally changed the way that we get along with each other.

Fantastic book and a must-read!

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