

Produced by and for autistic people

The *Spectrum*

Edition **98** April 2019



National
Autistic
Society

The Spectrum

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

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

The Spectrum is available at

www.autism.org.uk/thespectrum

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

Editor: the Goth

National Autistic Society production support: the Content Team

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

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

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The Spectrum is available in **large print** on A3 sheets (double the size of this page). If you need large print, please let us know using the email address or postal address above.

Contributions for the next issue should reach *the Spectrum* by **13 May 2019**

Welcome to the April edition of *the Spectrum*.

I hope that you like the completed new look of this magazine. By “new look” I mean not just the design and brand, but also the web version and the online archive, which is now as complete as possible.

Naturally, since the beginning of the year, anything appearing in the magazine is also on line — one day we hope to link all the articles on a subject to one another, though this is a very big project. Then there will be no need to search for them laboriously! That’s the reason why I had to change the rules (on page 19) to allow the NAS to use any contributions which appear in the

magazine in other online media, which currently mostly means Facebook and Twitter. We can look forward to a day when, rather than receiving an e-mail alert that the latest edition is now available, we can receive the alert of our choice: e-mail, Facebook, Twitter or whatever comes along in the future.

I know a lot of you have no interest in this, and want dependable paper, so if that’s you, please don’t be upset by such developments — paper continues, and book sales have not slumped as was once predicted.

Yours,

the Editor

the pets edition — suggestion for next issue on page 9

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Winston

by Willow

My dog is called Winston. He's a french bulldog. I painted this picture of him. He's two. I have Asperger's. (I will always keep the name by the way.) He's my emotional support. When I am having a hard time, stroking him and cuddling him is medicine for my soul. I talk to him all the time. He's my best friend. He gets me out of the house for walks when, despite being a very outdoorsy person . . . during meltdown, the thought of stepping outside can be just too much.

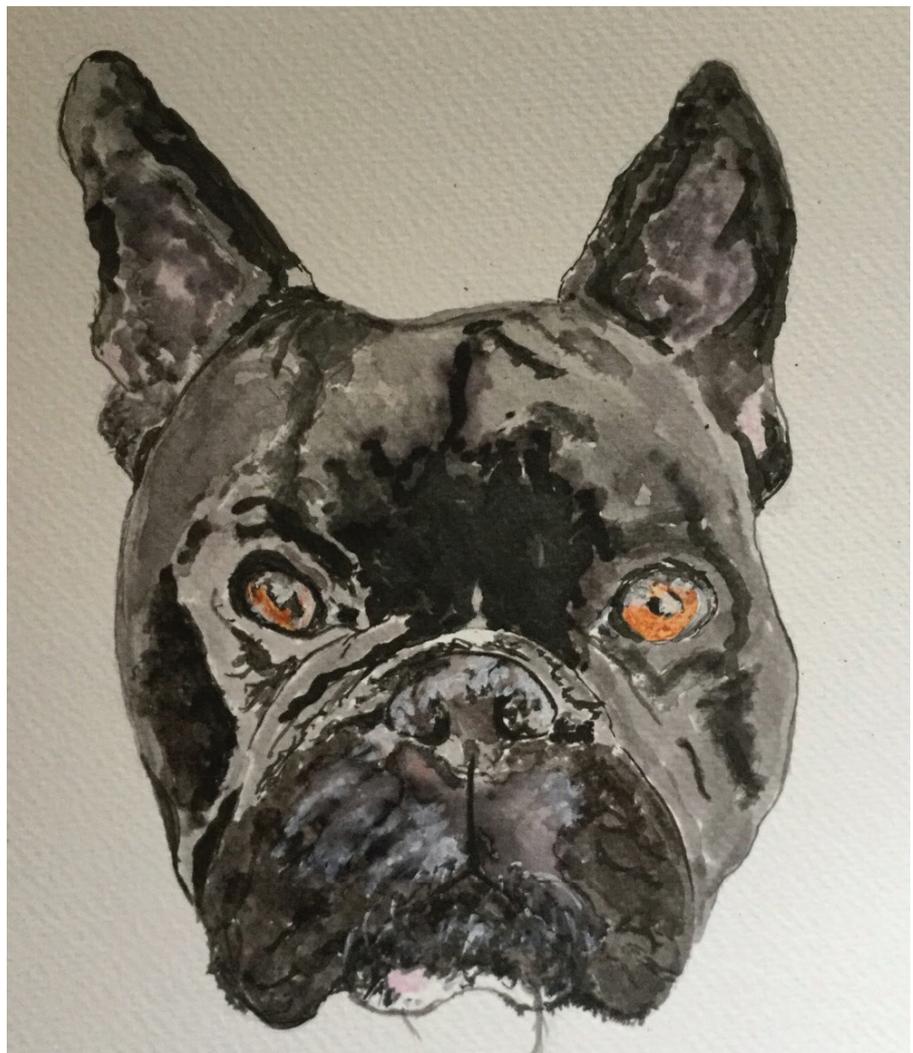
Especially when sudden change happens and I've fallen down what I call the rabbit hole of utter confusion (this means I feel like I'm falling and there's no bottom, I feel that out of control) I grab the lead and his favourite ball, wrap up warm and off we go, and once I'm out there, my mind becomes more relaxed, I get back into the present moment, emotions aren't taking over any longer . . . clarity creeps in pretty fast as I take in the wonderful sights of the Mother Nature all around me.

I love having fun with him, no matter how bad I feel, playing ball with him, exploring the woods, watching him sniff every lamppost with equal enthusiasm and listening to the way he snuffles with his nose touching the ground, sounding almost pig-like, suddenly everything isn't so bad and I laugh a lot — it's because he is so funny

that no matter how bad I feel, when I hear that I cannot fail but to laugh out loud every single time! If you heard it I know you would laugh too!

How wonderful he is without knowing it. Well maybe he knows, he's totally spoiled!

And every time I come home, I am feeling much better and I've had fresh air and exercise, connected with nature, and had fun with "man's best friend" — well it's just the medicine for the intense pressure and stress of an Aspie meltdown. Thank you, dear Winston, I love you.



Dear *Spectrum*,

as I am a real-life Crazy Cat Lady, I thought I should send you a few of my thoughts about pets. Specifically cats! I would like to talk about the enormously positive effect they have had on my and my husband's lives. He too is a proud Crazy Cat Man.

We “acquired” our furry pack of ten cats (officially known as a clowder or a glaring) before either of us realised we were autistic. Having that many cats and being “crazy” about them should probably have alerted us to the fact that we were a little bit different. Maybe it did to other people, who knows, but I do know that for us it should have been in the diagnostic criteria!

We did start with two children. They grew up and eventually moved out. At this point the cats moved in — one by one and two by two. Some rescued, and some “posh” pedigrees. We didn't exactly plan to have ten fur babies but somehow each of them purred their way into home and our hearts. Each time the gang went up in number, the surprised looks and comments from friends and family increased and the more difficult it became to justify our reasoning. We couldn't justify it to ourselves! All we knew was that we had struck gold and had become addicted to their fluffy little faces, naughty personalities and, above all, unconditional love. We stopped at nine but in fact nine was an odd number and it was inevitable then that this fact would be used as an excuse when kitty number ten appeared and needed a home.

Why so many? people ask. How do you cope with all the work and cleaning up after them? How can you afford them? Do you know all their names? (Yes, that really was a top question.)

Well these fluffy little souls ask for very little in terms of care and cost compared to the amount of joy, peace, relaxation and oxytocin release that they bring. Firstly, I needed a new special interest (I did need another one, honest!) and cats fitted that bill very nicely. Just had to buy a few more shelf units to store all those cat books and magazines on. Secondly, I have a lot

of physical problems and the mental problems that automatically come with them. I needed a good form of therapy and cats was it — just ask my doctor. Thirdly, my husband and I apparently have poor resistance to feline wiles and in this case resistance was indeed utterly futile — they had us at the first twitch of their whiskers. In my opinion, however, we must have rather good resistance because there were 30+ cats and kittens in one shelter that we went to, but we didn't come home with all of them did we? No, you see? Plenty of willpower really.

I was only diagnosed as an Aspie in 2016 (just over two years ago) at the age of 46, and my husband in 2017. It was at this point that living with so many cats finally made sense to us both. We both find life difficult in so many ways. We find people difficult. We found raising our children extraordinarily difficult. Cats are non-judgmental. They don't ask for much. They absolutely ooze calmness, peace, tranquility, acceptance and understanding. They don't answer back. They don't take more than they need. They are always there for us and they entertain us each and every day with their wonderfully varied personalities. Who wouldn't aspire to all those traits?

Our motto is definitely to “be more cat”. Our interest has also extended to big cats and whenever we can we support them too. We love all animals as well, and we could definitely see a place for a dog in our hearts and home too, were it not for the current residents having other ideas. But we do feel more attuned to cats over dogs, as dogs tend to be a little more needy and lively than cats. Being Aspie in a neurotypical world is very stressful, very tiring and very difficult. We *need* ten cats. We adore them, worship them and would do anything for them. In return we receive so, so much. They have also taught us much. And they, in return for their therapy services, receive oodles of love and attention, safety, pristine toilet facilities, plenty of playtime and toys, good food, fresh water, cleaning services, excellent medical care and cosy places for all personalities to sleep and hang out.

Vanessa

two letters

Dear Goth,

thank you for the latest copy of *the Spectrum*, which was fascinating. I would like to contribute an article for the next edition.

I have worked for many years looking after horses, as I lived on a small farm and so took on the task while my family were on holiday or at work. I find horses are very intelligent, and are chatterboxes, which may surprise people given as they cannot speak but they use body language to communicate with each other. For example, if they pull their ears right back, that means you are in trouble so back off! If they are facing forward, then they are fully focused on you and looking to see if you are a leader or can be led. If you can be led, then they will try and lead you by making you do what they want which is give food. They can be so fun and you can see their personality emerge the more you bond with them. Syd was quite laid back whereas Mulligan was a clever horse and picked up training faster, but did tend to bully Syd, which was not nice but is herd behaviour. I also took on another five horses for a neighbour and these were fun as one was a stallion, one mare and a filly, as well as a gelding. The stallion was called Donkey as he looked just like one with his grey colouring. He could be quite a handful at times and I often had to leap over the stable wall to escape his temper but all good fun. The mare was known as Silly due to her nature but I loved her as she was so wonderful to be with, as she loved a fuss and used to groom me using her teeth to rub along my back — this wrecked more jackets than I can count! Dylan was the gelding and was so laid-back it was a wonder he could stand up. He was always on the hunt for extra food. I found horses so much better to understand, once I learned to read them, compared with people, as they are so loyal to you and I had total trust in them.

I also love cats and am sad that I am not allowed to keep one in my current home, although this did not stop me from letting one in to dry off last week. I came home from the library and heard a cat calling, so called it and it followed me into my kitchen. He was a bundle of joy and I soon dried him off with a towel which made him purr non-stop. The rest of my house became a playground and I loved making a fuss of him, but sadly I had to let him back out due to the no-cat rule, but I hope to see him again should he wish to dry off. Animals can give so much pleasure!

Nick

Thank you, Bruce, for enlightening me about high-functioning Asperger's. I recently met a man who is a high-functioning Asperger's person. I didn't suspect "anything wrong" when I met him first but I started noticing little things which would cause a bit of annoyance to him: like if I met someone in the street I got the impression that he was a bit frightened of being introduced, reluctant to come for coffee, etc. Alone he is great fun, and likes to make double-meaning jokes.

Now for the serious business! We have become lovers (he is 75 and I am 73) so no worries about taking advantage! We have both been married before so know the ropes! I am wondering if people with Asperger's have any obsessive (dis)attractions which might cause dependence on me as the new partner, in my case my new partner is partly sighted but is independent and was a pilot in his working life, now retired of course! Another thing I have noticed is that he never asks if I am in good form: I am a healthy woman, but I recently fell down the stairs and cracked a rib. He didn't once ask if I was getting better or anything about why I fell. Is this normal for Norfolk? (NFN pun!) I have become quite attached to him *but* feel reluctant to undertake becoming a life-time carer to someone with this syndrome, partly because I don't think I have ever met anyone like him before, and am therefore in a bit of a quandary. One other thing, he seems to get upset in restaurants if everything isn't hunky-dory. Usually it's about the way the table is laid or something that to me seems trivial! Apart from that, in the shower he seems to want to scrub himself until his skin is red! He showers every day, so isn't filthy! Are these the types of obsessions affecting Asperger's people?

Ita

Pen pals

Pen pal number 278

Hello. My name is Emma. I am 34. I live in my flat with some support. I was diagnosed with high-functional autism only in 2015! It has taken many years to get a diagnosis.

I enjoy looking after animals; at the moment I have a cat called Leo — he's now one year old. He keeps me busy. I enjoy spending time with my family and friends. I enjoy going to church, arts and crafts especially jewellery-making, crochet, glass-painting and card-making. Going to see concerts and musicals. I like to write stories and poems and I also like watching some soaps especially *Coronation Street*.

It would be good to hear from you if you have similar interest.

Pen pal number 279

Hello, I'm Sian. I'm 29 (although I turn 30 in just a few weeks — eek!). I live in Cardiff. I was diagnosed with Asperger's a couple of years ago and am interested in getting to know other autistic people.

My main interest is autism. I love reading, researching and writing around it, but I also like to read other topics. Other things I enjoy include keeping fit, spending time in nature, travelling, and watching films and YouTube videos. I'm a big music fan, mainly acoustic singer songwriters, chill, indie, country, but I happily listen to most genres.

If you are a similar age and share some of my interests, then please get in touch! I look forward to hearing from you :)

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 280

Hello. My name is Michael, I am 49 and I have Autism. I would love to hear from anyone, especially America or New Zealand, who is looking for a pen pal.

My hobbies are listening to music, especially heavy metal, flying remote-control planes, fishing, watching TV and London Irish rugby.

I have seen Slipknot in concert and have been to Download festival. I visited America to see the Tennessee Titans play and I loved the food there, especially the spare ribs!

Pen pal number 281

Hello, my name is Rafe.

I'm 18, live in Leicestershire, and was diagnosed at 13 with high-functioning ASD.

I'm very much into anime of all kinds, as well as the songs associated with them.

I've also enjoyed some Nintendo games since I was young, mostly Mario- or Pokémon-related ones.

I'd like to talk to anyone about these things, especially those around my age. Looking forward to hearing from you.

Pen pal number 284

Hi. My name is Matthew and I am 38 years old. I have Autism and according to my diagnosis sheet, not a little bit, a lot.

I am educated to post-graduate-diploma level. I work in a supermarket, but live at home with my parents.

My interests are varied. I am: learning the guitar and violin (self-teaching). Though I'm much further on with the guitar than violin. Magic. Yes, I am a magician, who thought of performing to an audience at a try-out gig at the Magic Circle. This was pre-diagnosis and I haven't performed in public since. I just perform for my nephews, who love it. Other interests include theology, and I am trying to write a book about a character with Autism.

Would like to hear from people via letter or email. I have problems maintaining friendships though.

Pen pal number 282

I like traditional poetry,
But dislike modernistic poetry
I've written traditional poetry and three short stories
Would prefer ages 55 to 65 or a bit for pen pal
I am knowledgeable about natural history
I identify with Chris Packham in type
I also like gardening, walking, and music.
My name is John

Pen pal number 283

My name is Savannah. I would like to pen pal with someone that likes my interests. Disney movies, DreamWorks animation, anime, manga, musicals, scary movies, thrillers, comedies, cartoons, animals, TV shows, *Imyasha*, *Ranma 1/2*, *Sailor Moon*, *Naruto*, *Aggretsuko*, *Riverdale*, *The chilling adventures of Sabrina*, *True blood*, *Once upon a time*. I like trying different foods and I like to learn about other countries. I would like to travel to different countries. So if you're interested to be my pen pal send me an email. Thanks.

Pen pal number 285

Hello, my name is Lucy and I'm 16 years old. My interests are: art, sketching, drawing, anime, kpop, animals, Nintendo, gaming and astrology.

Signing up to this in hope of making a friend who would listen to each other's problems and struggles, or really just making a friend in general that I can talk and relate with :)

two letters and a notice

To Ji

Yes, we are sensitive souls. This is true, whether it is physically or emotionally, and also explains why we are smarter than the average bear, Bobo. In other words our intellect is as sensitive and aware as the other parts of us. People who are mentally unaware are not going to be emotionally or physically sensitive, are they? You cannot expect anyone to have only one or two of these faculties at a heightened level but not the rest can you? It doesn't make sense. True, communication may be difficult but then the insensitive tend to drown out the sensitive with their noise, aggression and general lack of awareness of others, other life forms, don't they?

Tony

Dear Editor,

I am writing this letter in reference to the subject "What does Autism mean to you?"

Being diagnosed eight years ago.

It has made me realise a few things.

Things I wouldn't have usually picked up on or pay any notice.

If sufficient material is sent in, the theme for July will be **special interests** or **repetitive behaviour and other stimming**. 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 expect interests and stimming 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!

Autism to me is something authentic and original.

In the sense that, of course Autism varies from person to person.

It is a crazy world out there.

It is hard to know who's on your side most of the time.

Who can you trust?

Is there anyone out there that understands?

Who is there through the highs and lows?

Who truly cares or accepts you for you?

There are so many questions, but the answers don't always come so easily.

I agree, everybody needs someone to some degree.

Someone perhaps who can enjoy life's pleasures.

There is so much going on.

But, the questions I have are:

Do autistic people have a voice in issues raised?

What makes autistic people thrive and show off their potential?

Is it the case that you are autistic (you are automatically at a disadvantage)?

Have a good evening,

Otis

letters to the Editor

Dear Goth,

for many years, research has focused upon treating children and adolescents with autism-spectrum conditions with repetitive behaviours or special interests. These behaviours were viewed as detrimental, reducing opportunities for socialising and learning. However, recent studies indicate that repetitive interests may increase explorative learning skills, as well as being pleasurable and managing negative emotions. Given the debate, I would like to suggest the topic of “special interests” for a forthcoming edition of *the Spectrum*. Reflections about how special interests (for example, a love of football statistics, Marvel comics) have influenced a person’s life would be a very interesting read. It may also help inform researchers and clinicians as to the merits of trying to intervene in this area.

Regards

Patrick

Dear Goth,

I wonder if there may be space in *the Spectrum* to invite people to try cycling? I am a keen club cyclist and cycle around the moors six days a week. Recently, though, I had to take a break from my club as some unkind comments were made about me that upset me. I have gone back and had a great day, but my thoughts are on encouraging people on the spectrum to go cycling as I feel that there is little provision and understanding if you are autistic. I am looking to lead a short ride next week for my local support group. I am due to be interviewed by *Cycling weekly* to raise the issue of autism and challenges we face. I am amazed I can even ride a bike as I have poor co-ordination. I do find that being on a bike helps me cope with this crazy world we live in and I would like to encourage others to try it and enjoy being out and about and the all important cafe stop! I hope this may be of interest to you but I do understand about space constraints.

Nick

Dear Editor,

I have worked in four paid jobs. And in all of my paid jobs I got bullied. It is a long story why I got bullied in all my paid jobs but it wasn’t nice at all. Some people don’t know how to treat people with disabilities. I have had three voluntary jobs and luckily in all of my voluntary jobs I didn’t get bullied and the staff treated me well in all of my voluntary jobs. So there are nice and understanding people in the world. I am sorry to all of you readers who are getting bullied in paid or voluntary jobs.

From,

Selina

I worry about printing pieces about bullying (or other suffering) as I know it causes many of us distress to read about it. But it also lets us know that we are not alone or unusual, that others are going through similar experiences and will understand if we talk about how we feel, Editor.

Thanks to the Goth and everyone who made the January issue such an interesting and heartfelt issue. I’m sure previous issues were great too but I’ve only just got over the change from paper to online, and have also only recently got around to trying to join in with the autistic community.

In response to Max regarding a new therapy for people with autism, this sounds like a dream come true, and could actually help people reach their full potential, rather than simply help them move from unemployed to employed.

I also like Peter Myers’ cover picture very much. And thanks to Anne-Laure for her encouragement in speaking up.

Further note to the Goth: my email address can be passed on to any of the above people to be put on their mailing lists or whatever. However I will understand if this sort of thing is beyond the scope of your role,

Helen

Disappearing into an autistic mind

by Eizzah

When I, Zach, disappeared in my best friend's mind, it was such a strange experience. I am guessing you are all wondering how it had happened.

Well, it all started when my best friend, Chloe, came round one Tuesday afternoon. We were raving like lunatics to some dance music I had put on in the living room. Chloe was carrying her blue notepad with her, in which she liked to write stories. I noticed that she would scribble down an idea every so often, usually in between dances, when we were having a break.

When my mum invited a friend over for a cup of tea, Chloe would sit down and draw portraits of them. They were so engaged in general social chit-chat, that they didn't even notice. Chloe often expressed clearly to me about how often she wished she too could talk like a neurotypical. She found their language hard to understand. Chloe would describe it as being like travelling to China, where you wouldn't understand Chinese.

Chloe was often confused and anxious. A part of me wished I could take this pain away from her, and trade places. She would assure me that everything was fine, that autism was a gift, and that it was a blessing to be autistic. However, I often doubted that she was telling me the truth.

"Zach," Chloe said to me after we had finished dancing, "do you really want to know truthfully about how I feel?"

I turned towards her. "Yes," I said.

"Hold this notepad."

As I held the notepad, I began to spin around and around. The scenery started to change, and I saw that I was at the gates of this school. I looked upwards at the sign on the gate. "St Mary's," it read.

By the gate stood a boy, he looked like he was only 12 years old, and had short dark hair. Next, a blue Astra pulled up. Out of it came a much younger-looking Chloe, and her older brother. As Chloe stood by the gate with her brother, the boy would make faces at her and mimic her autistic symptoms. It was a long wait before the headmaster arrived, cycling along on his bike.

The scene changed again, and Chloe was sat in assembly, in the school hall. There were rows of chairs, and one side was for boys, while the other was for girls. Chloe would place her chair slightly away from the other girls, while they were sat together. Whenever she tried to sit near them, they would laugh and move their chairs away.

As they were singing hymns, the bullies would make fun of Chloe's voice. When they had finished singing, the bullies would pile the hymnbooks onto Chloe's chair, without her noticing. This was because they knew Chloe would sit on them, and make a fool of herself.

Mrs Brown was showing Chloe's artwork to the assembly. It was a collage, containing photos of friends, that she had made outside the school.

"I didn't think you had any friends, Chloe," said a bully that was sitting in front of her.

The bully was a girl from the class below. She often sat in Chloe's classroom during break, as she was friends with some of Chloe's classmates. The bully once said that she liked everyone. Chloe had hoped that she liked her too, but her heart soon sank when the bully went on to say, "Except for some people, of course."

To be continued . . .

Author's note: this story is based on a real personal experience.

Pets

by Tony

When I look into my dog's eyes, I see simplicity, honesty, perfection and love. Sadly, I cannot see that in adult human eyes, but the glimmer exists in children's, before adults knock it out of them and they become the conniving, dishonest, frightened beings we recognise as neurotypical human beings.

We only have one dog left now — Jack the lad, Jack in the box, Jack of hearts. He is growing older and more arthritic with time. He is also imitating our last old dog, Midge, which fought its way back from a stroke to full health (lopsided head, with left bias, to fully upright again) before succumbing to the inability to gain sustenance from any food, through suffering perpetual diarrhoea.

Holly, the old Labrador we had before her, was full of joy, but they didn't get on. One night, shortly after we obtained Midge, she panicked, bumped into Holly and bit off part of her ear. After this incident Holly was badly shaken and within a short period of time developed diabetes.

Me and my wife's first pet together was Corrie. She had taken possession of her as a puppy and met me in her

twilight years. She instantly recognised me as a fellow traveller through life and we got on well from that instant. If we hadn't got on well, as my wife pointed out, that would have been me out the door, not the dog. When she eventually passed away, we were both by her side. She looked from left to right, making sure we were both situated near her and died shortly after midnight.

We had looked after a friend's dog, when she went off on courses, at a period after this. Eventually she said that we might as well keep Ludi as she was with us more than her anyway. Shortly after this we also acquired Holly, although our original intention was to get only one new dog.

We got Holly from a friend of my wife. We picked her because she picked us, coming straight up to me when we viewed the batch of puppies. On the way home, she started off on my lap, venturing up to my shoulders then onto the parcel shelf at the back of the car. The first few nights she slept on my head like a wig or under the covers with her rear end sticking out.

Her and that bed. She was only aggressive twice and that was when my wife tried

to move her position. She was like a typewriter carriage. Every time you turned over in bed, she lumped up against your body in the new place, until eventually you found yourself on the edge or with the duvet totally off you. If you tried to move her, she growled in displeasure. My tactic was always to get out of bed and move to the other side, but not Margaret's.

Ludi died of a haemorrhage when we lived in Thurso. She had run like the wind, chasing deer and rabbits. If we ever lost her, she never lost us. She would calmly turn up at our house, while we were out, frantically searching for her in the last place she was seen. She ate dead rabbits that were so mouldy she would end up bringing them back up, ears and feet mostly. Finally she became so arthritic that she struggled to walk, let alone run.

Holly became ill when we moved to our present location. Years of injuries, and general wear and tear, dragged her down. During her youth, she had run across the road and a furniture lorry had hit her, dislocating one of her back legs. In her old age the joint became swollen and slowed down her pace. She developed bladder stones on top of

this, which meant she had to go on a special diet. This necessitated me having to walk her round the village in the early hours of the morning as well, in an attempt to dislodge them enough, so that she could urinate but this didn't always work. Come the dawn though, she relaxed at the thought that she had survived another night and the liquid flowed out onto the carpet.

This was not the end of her woes, though. She had diabetes which led to daily injections by me, and her slowly going blind and deaf. I had to sleep downstairs for the last year of her life as she could no longer get up the stairs. When the vet came to put her to sleep, he wanted to give her the fatal injection in the kitchen but she dug her heels in. I told him it didn't matter as she had already messed on the carpet enough that we were going to have to replace it anyway, after she was gone. We also had Jack at that time and I shut him in the garage out of the way. He and Holly were best friends, so he took her departure very hard, howling in such a mournful way in the garage, I felt guilty about putting her down for years afterwards.

A few months before Holly developed diabetes, we acquired Midge. She didn't get on with Holly and shortly after we got her, she accidentally bumped into her in the middle of the night and bit off a piece of her ear. The

vet turned it into a cauliflower, which meant all feeling left it. Another violent incident led to Midge ripping the dead ear from top to bottom, requiring the vet to staple it back together. Holly, however, was ecstatic as she had won the fight with her old adversary because she felt no pain when Midge attacked her.

Midge was a severely traumatised dog and even after Holly died, she attacked Jack for no good reason. She was old when we got her and because of this it wasn't long before she too couldn't make the stairs. Once again I spent several months sleeping downstairs, while Jack went upstairs with my wife.

I was brought up with cats but my wife was allergic to them. My first cat, when I lived at home, was a white-haired kitten. It was accidentally killed when a draught from the back door slammed the front door on it. My mother frantically rushed around the neighbours, trying to find a replacement before I came home. When I arrived back from school, apparently my first remark was, "My, Whitey has grown since I left this morning!"

The next pet we had was a ginger cat. She gave birth to several kittens before dying. We kept her last three — a ginger tom, a white tom and a multi-coloured female. The ginger tom got shut in a neighbour's shed and was

found dead a few days later. He had an ulcer on his neck that we treated with a green cream that the vet gave us. It shrunk down to the size of a sixpence but always flared up again. His brother succumbed to the same problem, when I was away at college. Male cats always get into fights, so it is not an uncommon thing for them to end up with this injury.

My father dug a grave for Ginger and found a shoebox to act as a coffin. My brother painted a wooden headstone and I spent a night-time vigil kneeling by the place my pet was buried. I had bought an illustrated candle, which burnt down the inside and as it did this it illuminated the picture on the outside.

Visiting Norwich, a market trader talked me into buying a budgie. Unfortunately, my mother got fed up with Spoot, splashing bird seed all over the carpet and so he was banished to the small room by the stairs, where he became neglected and sadly died. Yes, I felt guilty about this and still do.

The only other pets we had were goldfish, which we got when I was very young. I tried to bury them in the garden, to see if they could swim through the soil as well as they did in water. Luckily my mother caught me and saved them. She bought exotic fish that were kept in a tank. Eventually they all died from a fungal disease called white spot.

My journey in getting an autism diagnosis

by **Katrine**

I am a 55-year-old adult with diagnosed autism-spectrum disorder. I was born in 1963 in Edinburgh and I lived with my parents and two sisters in Jedburgh. I along with my family moved to Ashington in Northumberland, the June of 1965. Then suddenly without much warning we were moved from Ashington to Plaistow in London in January 1971. On my seventh or eighth birthday I invited my school friend and other people I knew to my birthday party. It was my only birthday party with anyone from school as I was mocked because I gave them a talk about all I knew about astronomy which they found boring and felt that it was an old-fashioned birthday party. It was not a buffet one, as I had a traditional sit-down tea. I was deeply hurt especially that they did not find my astronomy talk interesting as it took a while for me to write. I greatly struggled at school especially with my handwriting. I was told I had poor comprehension skills. My school reports from my schools in Plaistow were very brief, only consisting of one line or two words. Most teachers said I tried hard and that when books were being passed out, I would be missed out. I know that I was deliberately missed out. I had poor grammar, spelling and handwriting, reading and arithmetic skills. I also had extremely poor co-ordination and balance as well as eye-to-hand skills. I had very weak wrists as well as my back and a clicking/flexible jaw. I still have very weak and flexible wrists and a clicking/flexible jaw.

I was sent to a child-guidance clinic in 1973 which I never found out why, as I thought it was due to my epilepsy. I would stutter when under pressure, and I was an excitable child and was always full of energy. I was easily distracted as I had a very short attention span. I never tried to fit, as I did not know I was different and did not have any coping strategies, as when I could not cope there was not anything I could do to make me feel better.

I always struggled at school and even more so as I did not have my support of my cousin Sheila when we lived in Ashington. I was bullied a lot in Plaistow because of my unusual Northumbrian accent. I have always struggled in reading fictional books but would prefer to read reference books, especially encyclopaedias, my mother's nursing medical books, large dictionaries and atlases. I was enthralled by the Apollo moon landings and had a very basic understanding of astronomy and meteorology which I would have liked to pursue but did not have the same opportunities that I do now. I have always had sensory sensitivities to noise but as I have got older it has got worse, not less.

I was taken out of school at the age of 12 as I was told that I could not cope with going to the Prince Regent Lane Secondary school in Plaistow, as they felt it would worsen my epilepsy. My mother once remarked that she told me that I was like a square peg trying to get into a round hole and that the educational system had failed because it did not appreciate my uniqueness. I waited until 1978 until I was found an appropriate school, a Catholic boarding school for children who had epilepsy and I was only there for a year and I was not put forward for any exams when I was there.

During the school holidays, and when I was taken out from school, I read reference books which included dictionaries, encyclopaedias and atlases. From 1979 to 2013 I have been mainly in employment-training courses, which did not help me even though I worked very hard and I was held back by my lack of "soft skills" and no social network. In November 2013 I referred myself to the mental health charity MIND where, through their help, I was referred for an autism diagnosis which I received on the 13 November, 2014, but

an article (continued) and a letter

was not offered any post-diagnostic help. My mental and physical health deteriorated greatly and I was referred in 2017 to the mental health outpatient clinic where I asked to be referred for post-diagnostic therapy, which I have finally accepted as it is generally only given to those between the ages of 18 and 30.

Dear *Asperger United*,

hi, my name is Dan. I am writing to pass my comments on a few subjects related to AS but as well I wish to share my story. I'm not entirely sure: I think it's got something to do with talking to somebody who can really understand. What I mean is, telling my story to somebody else with AS, so I'll start from the beginning.

From about the age of 7 I noticed I was different. I had next to no friends whilst everybody else had plenty of them. I moved about a bit so went to three different first schools, two different middle schools and stayed at the same high school. It was upsetting because every time I moved school I told myself that I would use this as a chance to make friends and keep them but I never managed it, of course, because at break times I wandered around alone.

I was a big target for bullies and I was also overweight, ginger and wore glasses, which made me stand out even more. So you can probably imagine the amount of taunts I put up with on a daily basis and I tried everything to get out of school. I pretended I was ill, tried to sleep in but curiously never "bunked off". This is because I was told it was completely wrong to leave school when I'm not supposed to. The worst thing was I couldn't do much out of school either because I used to get chased by bullies around the streets near my home.

Anyway, I moved to the country and my house was in the middle of nowhere, so I only had to worry about it at school now. I tried to keep my head down as best I could. By now I was in middle school, sixth year. I was very good at hiding, plus I played football a lot. You don't need friends to play football usually — you

As an adult my sensory sensitivities have got a lot worse. I rarely ever go and visit shops, supermarkets and shopping centres due to extreme sensory overload of unfamiliar places, bright artificial lighting, crowds, loud as well as sudden noises and strong fragrances and chemical odours and smells.

just join in. Nobody notices you, although there were a handful of times I wasn't allowed to play because of "unfair teams" or other excuses. Towards the end of year six a major thing happened. Once again I found myself being chased. Unfortunately, I ended up leading myself into a secluded area. There were about four year-eight boys and they messed me up fairly bad but thankfully when I went to hospital they said I would be alright, but I had one heck of a shiner on my eye after that.

I was taken to a different school and the boys who attacked me were not punished because nobody saw them do it, plus I wasn't even sure who it was. I could recognise their faces but I was never good with names.

After that I saw a lot of people — educational psychologists and other professionals — but none of them ever mentioned AS. Similar things happened throughout my school years but nothing as major as the attack. Then a woman came to see me. She told me she was a psychologist and I had been referred to her. Anyway, I was admitted to a place called the Roycroft clinic. It's a type of hospital for people with mental disorders. I was assessed and was given a formal diagnosis of Asperger syndrome and when I learned about it I started to realise why my life had been the way it was.

Now here I am living at the clinic, learning new social skills every day, slowly improving and getting prepared for adulthood. The only question I was asking myself was how come it took so long to be diagnosed with psychologists seeing me at school. I thought one of them would have picked it up. However, I am lucky because the help I am getting and my life ahead of me seem to be making up for it!

Fear and anxiety

by David

Hi, readers of *Asperger United!* I am David, the Compulsively Creative Man. I want to disclose my history of fearfulness and acute anxiety, and conclude with how I have felt after what I call a mindquake hit me when I lost my doorkeys. I am minded to write a far more detailed account.

At age 5, people said that I had bad nerves because of the War (consider German children from Hamburg, Dresden and such born between 1937 and 1944, who heard the RAF bomb German cities. Is there a simply *colossal* incidence of mental problems amongst these people compared with their peers born in Ireland?). My very earliest memories are of being scared of: steam trains, horses, dogs, waves and fireworks. At primary school in Sussex I was the butt of scorn because I showed these fears. Children called me loony, and how that hurt. For years I feared that I was a lunatic and would be locked up for life in a lunatic asylum if I disclosed what are in fact “pure OCD” hurtful, intrusive thoughts. A mega-mindquake hit me in 1953 when I was expelled from a grammar school merely for using swear words! This gave rise to scars in my mind that persist even now — a fear of offending people, particularly Christians like my late father. I will not elaborate how at remedial school the headmaster administered psychoanalysis, except to say that it gave rise to lifelong strife with my father. I overcame fears of fireworks and other things in those years.

I suffer absolutely overwhelming anxiety in any formal social situation, so I avoid them — dodging my parents’ funerals by conveniently spraining my sound leg! I overcame fears by climbing lofty mountains alone. When I had climbed enough precipitous peaks it gave me the confidence to face up to other kinds of fears. Since loss of my driving licence and onset of cramp when climbing, I can no longer extirpate my innate fearfulness in this way, so I have

reverted to the fearfulness I felt when I was a small boy and this bothers me in every waking minute. I am not afraid of flying but I have an absolutely mortal fear of missing planes, that gave rise to a confrontation with the police at Glasgow Airport in the small hours, because I had arrived at about 11pm to be sure of catching a plane that left about 7am.

I have written detailed accounts of several really hurtful social disasters including the occasion when Glasgow police picked me off a busy street and dumped me in a mental hospital.

In 1995, when I had read Goleman’s *Emotional intelligence*, I was hiking near Cumbernauld when a horse whinnied and I fled, then it whinnied again and I felt that I was about to die. Goleman explains the amygdalic shunt, which enables people to escape danger and refers to a sober Englishman whose reaction times were quick enough to escape the sinking *Estonia*.

I deduced that my amygdala greatly amplifies certain sensory inputs to give rise to frequent false alarms and this induces overwhelming flight or freeze in my brain, never any impulse to fight. I had a major row with my father about the Cumbernauld horse affair. He said that I had made it all up to justify my besetting vices!

In 2005 I forced myself to overcome acute vertigo in order to photograph a unique coastal feature. I dashed to and fro, peering through successive camera viewfinders and strode away acutely cognisant that I would always suffer physical vertigo. I also suffer acute social vertigo, as at a recent wedding, when I was absolutely sickened by the opulence and expense.

Fear of catastrophes abroad has paralysed me quite often and held me back from visiting countries I perceive as dangerous. I vacillated

about visiting Sweden this year. On Friday I had to decide whether or not to go, so I spent ages vacillating. I reasoned that if I ducked the challenge it would be much harder to summon the courage to book a trip anywhere in the future; Stockholm is a safer city than London! So I booked and paid for a week in Stockholm, then took a bus home to discover on alighting that I had lost my doorkeys and memory stick. This has given rise to by far the worst mindquake this year, after a workman made off with my wallet, and I had lost a cheap fixed-focus camera with exposed film inside. I shall struggle with words to define what has overwhelmed me in the past few days.

It was as though an atom bomb had gone off in my brain. Alone in my home I have been shouting abuse at myself. It is as though my father's ghost is beside me shouting at me that I am absolutely irredeemably flawed. I am innately careless, untidy, negligent, slovenly. I have no redeeming qualities; I have regressed to that guilty boy who in 1953 was dared by his classmates to say things like "I want to shag you." Since I have not had a career since graduating, I am absolutely crushed by guilt feelings for "being a parasite of Society"; I really hate myself after events like losing doorkeys. This self-disownment gives rise to grim stories where I project all my bad feelings into the protagonists.

Once a workman stole my chequebook and emptied my account. Though the status quo ante was soon restored, at the time I felt the way I do at this moment. All the pleasurable anticipation of my trip to Sweden has been replaced by an irrational dread so strong that I feel that I am being carried on a swift current over a figurative Niagara to something far worse in Stockholm.

Szalavitz, in a 2008 article in *New scientist*, collates findings about autism from autopsies of autistic brains and other observations. She explains how the amygdalas and related structures are greatly enlarged whereas other brain structures, apparently controlling social behaviours, are somewhat atrophied. She brings together findings that seem to prove that the brains of autistic children are overdeveloped and

damaged by everyday sensory inputs that are greatly amplified by the amygdala and nearby structures. It would appear that in my own case this explains all my fearfulness and anxiety. I can recall incidents of my primary school years that would agree with Szalavitz. Whilst this elegantly explains my malfunctioning brain, they cannot, per se, extirpate my fearfulness and anxiety. If perhaps my very own essay on the Szalavitz findings (on that lost memory stick!) had been distributed to all involved with dealing with autistics it might enable the police and others to understand how people like me are so overwhelmed with mental pain beyond the limits of language that we behave oddly.

I have to live with myself! After mindquakes I feel quite unfit to have friends or belong to society, so I have to banish myself. This greatly exacerbates the problem and it is amplified by other fears: that of wasting people's time or boring them and paramourly offending them with disclosures of my problems. I also dread situations where I am overwhelmed with emotions, for then I perceive myself as effeminate or childish. It is small surprise that I reject the Christian religion. In place and largely due to my frequent mindquakes, and all that follows from the mental distress, I have been spurred to invent possible management strategies.

If people are pitched into mental distress beyond the limits of language they desperately need to contact trustworthy people so as to disclose every hurtful detail and find by means of the collated experiences of mindquake sufferers strategies to restore the status quo ante swiftly enough to restore their dignity and self-esteem.

Readers, I want to set up an organisation where such people can turn for help. For we all need to forgive one another for lapses caused by our Asperger brains.

Postscript: my keys and memory stick were found after I had inadvertently dropped them in a box of cotton reels at a recycling centre, but please, readers, appraise my blackest feelings about myself and comment on my disclosures.

Pets

by Anne-Laure

Pets can give so much to their owners: affection, loyalty, company, an incentive to get some fresh air . . . But I also think that as a person with Asperger's syndrome there are peculiarities to my interactions with my pets that neurotypical persons may not be aware of. These are what I would like to share with you today.

A dog, two horses, and chickens are currently part of my everyday life. I enjoy a lot of quality time with them, which most people can imagine easily enough, but there are three aspects of my relationship with them that are not easy to admit, even to myself, and sometimes difficult to deal with.

Routines

First of all, when a new pet barges into my life, I have to rethink a lot of my routines. A pet brings a lot of change and, as many of us, I do not like change and I find it difficult to adapt. New routines have to be planned, tested, tweaked until they work both for the new pet and for myself. That is a time of unsettling, exhausting changes. Even getting up a little earlier and going for a walk with my dog before breakfast took me months to get used to. The bright side is that once the pet

fits into my routine, then I do not even have to think about schedules because everything is predetermined. Routines also act as motivation when the weather is horrible, easily overcoming any temptation at laziness.

Communication

My dog and horses require a minimum of communication from my part, either through words or body language. When I am close to, or in, a meltdown I do not want to communicate with anyone, and that extends to my pets. My dog often looks me in the eye while waiting for a command or for a toy and, when I am tired, it is as difficult to meet her gaze as a human's. My horses read and respond to verbal commands and to my body language pretty well, and keeping those communication channels clear and precise when I am emotionally drained is a real challenge. Sometimes I lose my temper and get angry even though I know this is only going to be a setback in our progress.

Perfectionism

Finally, I am a self-confessed perfectionist. I push myself to achieve as much as I can, to be the best person I can

according to my own standards. And that extends to my pets. My dog has to be the best-trained dog ever, my horses have to obey my slightest commands and my chickens . . . have to lay eggs (which they do). It is sometimes difficult for me to be patient while my pets get things wrong before finally getting them right. I think I have improved on that subject in the past few years but I still allow any failure on their part to cut me too deep. I need the strength and mental resources to let my rational mind rein in my fiery emotions and find the positives in our training sessions to keep believing in myself as a trainer and in my pets as the best pets that ever walked the Earth. We are getting there.

Those three areas in which I find it difficult to manage a life with pets are part of the reason why I shall never have children.



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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High Leigh Conference Centre, Hoddesden, Hertfordshire

Monday 12th August – Thursday 15th August, 2019

by the organisers

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