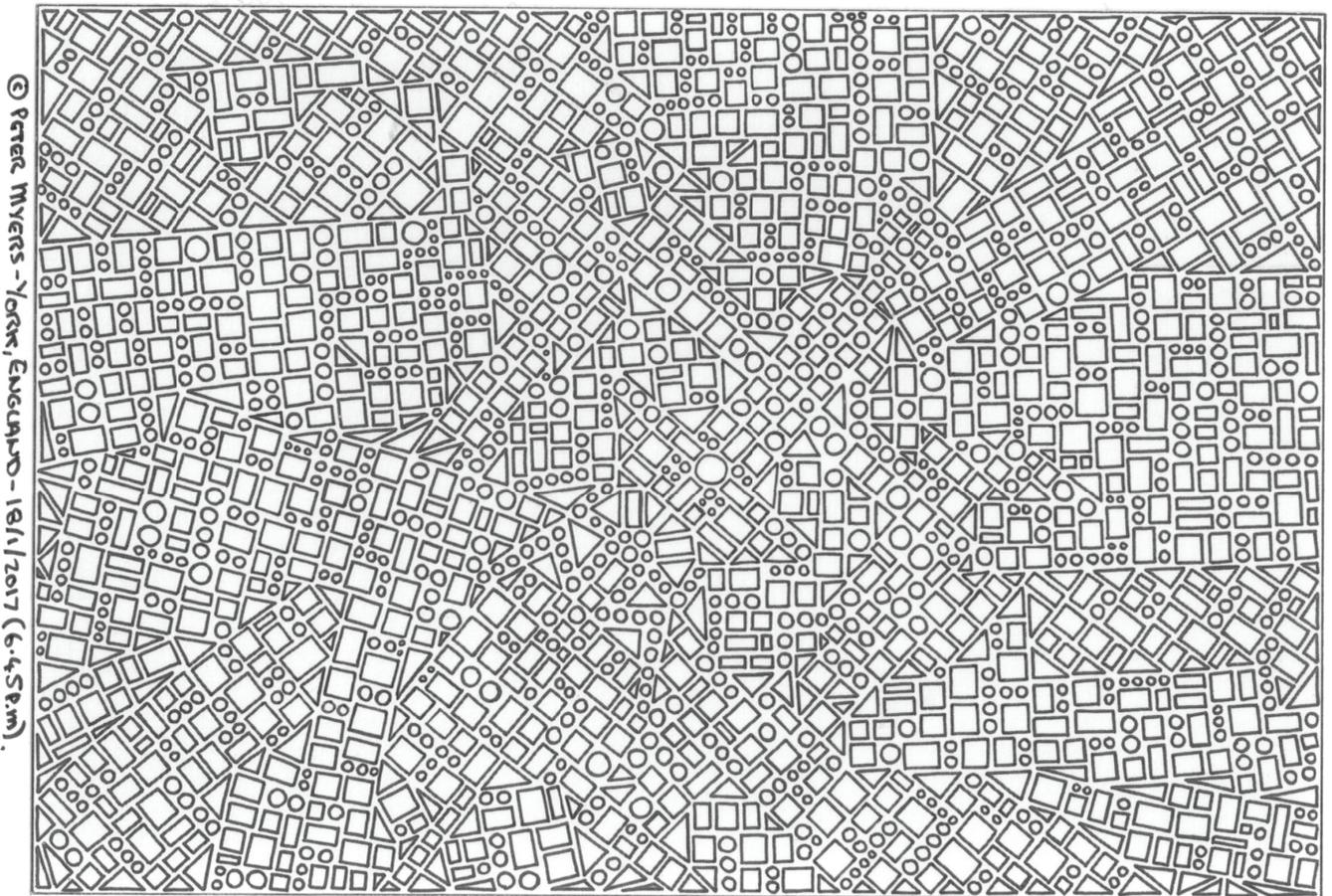


Produced by and for autistic people

The *Spectrum*

Edition **97** January 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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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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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 **11 February 2019**

Welcome to the January edition of *the Spectrum*.

I was very surprised that in this postbag I received almost nothing about one of the suggested themes for this issue — pets. So many people I have been in contact with seem to derive a significant part of their social life from having pets or working with animals (often as a volunteer) that I was expecting a massive postbag, but no.

Instead I got many more letters about the changes that are happening here, so I decided that letters and articles about change would dominate another edition — I hope this is okay, and please let me know if you don't like it! If

you don't tell me when I get something wrong, I will probably go on getting it wrong, so I need negative feedback as well as positive feedback to judge how the readership feels.

Do not fear, however, pet-lovers! Get writing, and hopefully the April issue will include lots of letters and articles about pets and animals. Or you could write in about why you think “pets” was an unsuccessful theme?

As ever, I look forward to your letters and emails,

Yours,

the Editor

the what-no-pets? edition — suggestion for next issue on page 5

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Hans Asperger: a response to the latest revelations on his war record

by Graeme

In recent times certain research by Herwig Czech, of the work of Hans Asperger, an Austrian physician, after whom Asperger syndrome, (a form of autism), is named, has laid charges on Hans Asperger of collaboration with Third Reich ideals of genetic purity by sending disabled children to Am Spiegelgrund, a “clinic” where they would be killed.

These revelations have caused much pain and hurt for those with a diagnosis of Asperger’s syndrome, with some being ashamed and not wishing to use that diagnosis or feeling dirty.

The main issue I have with this latest research is the conduct of Herwig Czech in publishing this new research and the way he froze out Steve Silberman when he was asking about information for his book, *Neurotribes*.

What has been done is put this research about Hans Asperger out in the public domain with no reference to the context of the time, thus causing the aforementioned hurt of those with the diagnosis of Asperger syndrome.

First of all, eugenics and sterilisation that the Nazis were infamous for, and now also attributed to Hans, was not invented by 1930s Germany. It was an American idea that they copied. Eugenics and sterilisation came from the Land of the Free — was there any mention of that in this research?

Regarding the context of the time, the concept of euthanasia of disabled children, an anathema to us today, and rightly so, was seen in the 1930s and 1940s in those placed under control of Nazi Germany (in this case Vienna in Austria) as acceptable and the way things were to be done. Even parents would request their own children to be euthanised if they were seriously disabled

as they were considered a burden on society, as well as not being eugenically pure. If Hans was selecting children for this euthanasia clinic, which he was not (it was his superior, Professor Franz Hamburger, a dedicated supporter of the Nazi regime), Hans was doing nothing more than anyone else in that place at that time.

They were dark and wretched times when much of Europe and some parts of Africa were under Nazi rule, and we are thankful that the Axis powers were defeated by the allies. We must ask how much of what Hans is alleged to have done is any more collaboration with the final solution than say the train drivers who drove the trains that took the Jews to the death camps? What about the railway signalmen who made sure those trains got there? Were they card-carrying members of the Nazi party as well? Should they too have stood trial at Nuremberg? They were complicit but were they fully culpable? This is why historical context is vital to understanding the past.

The other point that was ignored when this research was put out there was that if anyone did not abide by the Nazi line, then that could spell their doom. Some did stand up to them and paid a heavy price for that resistance. In that context we can very well see Hans going along with the appalling atrocities of the Third Reich, along with others, because of the consequence of not doing so.

A question I put to those wishing to remove Asperger from the lexicon, because this academic says he was complicit with the Nazis in the extermination of disabled children: if he was so much in agreement with Nazi doctrine and policies, why did he never join the Party of National Socialism like a number of his contemporaries (even by Czech’s own admission)?

feature (continued), a letter and a notice

As for his name on our condition, Hans never gave his name to it, which was done by Lorna Wing in the early 1980s. Hans never sought the honour of having his name ascribed to a condition. It was done by the lady who gave us the autistic spectrum and did a lot more for autism research and also had an autistic daughter.

Finally this has also been a distraction as eugenics is still being carried out to eliminate us. Why do you think they are looking for a test to see if there is an autism gene in unborn fetuses? Did anyone catch that news item on how Iceland is going to eradicate Down's syndrome? — how do you think they will achieve that?

Dear Editor,

I am writing to you because I read Jehovian's article *Theory of aetiology of Asperger syndrome (AS) partly due to extra-terrestrial (ET) genetic inheritance* in the July edition of your magazine.

This article struck a chord with me, because I recently published a novel which is based on a theory that extra-terrestrials inserted DNA in humans. It is set in Kent in England.

“If you were consulted, would you vote to have most of humanity removed from Earth?”

Who would you choose as your seven companions to restart a new population?

While the human race is at the brink of being cruelly exterminated by self-absorbed world leaders, Caila is one of thirteen humans who are pulled out of their ordinary existence by an alien species. After being consulted on the future of human existence, Caila is tasked with the start of a new human population, whilst discovering and coming to terms with her own mixed human/alien origins.”

A follow-up (parallel) novel, set in Canada's Ultimate East, is expected to be published in November of this year (2018).

The main character in this novel has been diagnosed with autism, is highly intelligent and in possession of alien DNA. In this novel, major roles have also been assigned to a number of highly intelligent children from a special-needs school. They are brilliant, but they do have some problems communicating with neurotypicals, especially their teacher.

I would like to offer Jehovian a set of hardback copies of my already-published books, and in due time, a copy of my new novel which will be published later this year.

Would it be possible for you to contact Jehovian, and ask him/her if he/she is interested in my offer?

For more information about these novels, please visit my website:

<https://www.haszit.com/>

Kind regards,

C Attleya

For your information, I have never been diagnosed as being autistic. However, people have suggested that I probably am, and they are probably right.

I have written to Jehovian, but I have no money to forward large items like hardback books! I have a small budget for forwarding letters and contacting people, but that's it. I hope that by the time you read this, Jehovian will have replied, Editor.

If sufficient material is sent in, the theme for April will be **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!

Dealing with change – courage is not the absence of fear

by Rosie

Change can be scary. That's what everyone says. For an autistic person change is not just scary. Change is being dropped into the middle of a desert with no map or direction. No resources or safety. It's unsettling and at times terrifying.

Change is inevitable. That's another one neurotypicals like to throw around. Unfortunately, there is no denying this. If you wish to pursue anything — a career, hobbies, or anything else — things need to change. The part that is always the most difficult for most to understand is that change, even with a great outcome, is still a horrible experience for an autistic. You could tell me I am not going to work on Monday, but I am instead going to meet JK Rowling. This is my ultimate dream, yet my brain will still scream at me that that is not the plan. I go to work Monday mornings and

this change doesn't make any sense to my routine. The outcome will not make going through the change any easier.

Below are a few ways I have developed to deal with change.

Safe zones

Starting work after university opened my routine to a lot of change. From public transport to changes in my environment and schedule. I compensated for this by boxing off safe periods of my day that were tightly planned. I got home and had the same food every night, watched my special interest show and fell into a very regimented routine to recover from any change I had experienced that day. If you live with people, it is important to involve them in these allocations of safe times and build routines that work for you.

"Plans"

When neurotypicals use the words "plan", "meeting" I very consciously put in air quotes. I remember the first time a meeting changed at work. It led to a meltdown because I had planned to face a challenge at a specific time and my preparation revolved around that time. Moving the meeting wasn't a shift in the plan, to me it was a whole new meeting that in no way resembled the previous plan. I realised after this that most people's work plans are more work suggestions. Categorising these as such has been a huge help. A meeting at ten o'clock is a suggestion of a possible meeting and I will prepare two options for my plan at ten o'clock, should it occur or not occur. This takes more effort beforehand but saves meltdowns, which are not something I want to happen nor recover from.

Black and white

I doubt I am alone in experiencing a small amount of change and my mind concluding that absolutely everything has changed. It has become increasingly important for me to break down what has changed and appreciate that much of the original is still present. That is, this magazine's name has changed, but the articles, the content and the authors are all still familiar. It is important to balance the fear with acknowledgment that familiar comforts are still present.

Acknowledge the courage

Experiencing change is hard and no amount of preparation or recovery will take that away. Fearing change yet putting yourself in these situations is brave. Acknowledge that it's a hurdle and be proud of getting through it.

Pen pals

Pen pal number 271

Hi, I'm Olivia and I'm 23. I got diagnosed with Asperger's at age 20, after struggling all of my life, and not understanding why. I'm bed-bound due to having severe ME, PoTS and several other illnesses.

My interests are: documentaries, audiobooks (anything non-fiction, from biographies to science or psychology), drawing (though I'm not very good at it haha), painting, animals and my Nintendo DS.

My current special interests are learning about cults and also about psychology.

I'd love to find people to email with!

Pen pal number 272

My name is Richard. I am 47 years old and I live in Stockport near Manchester.

I am a full-time carer for my mother. I was diagnosed with autism just over a year ago.

I also have anxiety and depression which have been part of my life for over thirty years.

I enjoy listening to music, computers and keeping up to date with technology.

I also like spending time by the coast and taking photographs.

I am a caring, non-judgmental person and I would like to hear from anyone with similar interests.

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.

more pen-pal adverts

Pen pal number 273

Dear Sir or Madam,

I would be honoured if you could help me to find a pen pal.

My interests are studying, collecting model cars, doing my Peer Training for Recovery College for last two years, collecting coins, paranormal, horror. I have been a Lord over a year now.

I would like people to write to me first, so I know who they are before giving them my mobile number, so I know they are genuine, and my date of birth is in 1977.

I don't mind if they have been in hospital or not.

They can call me John, and I don't mind if they are male or female, and feel a bit lonely because I will be there for them as long as they are willing to stay in contact with me.

When they phone me, it will be direct to me and it has to be after 9pm, when I am free to talk.

Yours faithfully,

John

Pen pal number 276

Hi, my name is William, I live in Wales, I am 20 and have Asperger's. I enjoy slapstick comedy, steam railways,

Pen pal number 274

Hello everyone,

my name is Ozflinders. I'm 49. My interests include: listening to music, creative writing, drawing, photography, and so on.

I'd really like a pen pal with Asperger's — your interests can be different: it's nice to live and learn.

Hope to hear from you soon.

Pen pal number 275

Hi Spectrum,

my name is Naomi. I am 18 years old and have just been diagnosed with Asperger's. I hope to be contacted by others my age or above. It's sometimes difficult to find people who have been diagnosed and know what it's like. I'd like to share my experiences and learn about others. I like music, henna, food, and spending time with people I love: laughing is a must.

Thanks,

Naomi

computer games, writing and many other interests. I would like to hear from anyone who is around the same age and looking to make some friends. Thank you for reading this.

Pen pal number 277

Hiya, my name is Rob. I'm 50 years old and I have high-functioning AS.

I live with my wife and two daughters (14 and 11) in Bristol.

I work for a care home charity, managing refurbishment projects and I travel across the UK. I love the long drives which give me plenty of alone time, and I'm happy with staying away in hotels a few nights a week.

I have had many obsessions over the years but am currently focused on DIY in my home and my current collection obsession is collecting woodcraft books — more than I'll ever read.

I love podcasts on my long journeys and I'm currently listening to hand-tool talks, but have recently finished many audio books from Bill Bryson, James Patterson and Sergei Lukyanenko: I love fantasy and sci-fi.

On TV I'm currently watching *The fringe*, *Criminal minds* and *Sleepy hollow* as well as *Bake-off*.

I enjoy lots of different types of music: Ben Drew, Amy Winehouse, Mary J Blige, and some funky dance music.

Would love to chat with similar-minded people.

Dear Sir or Madam,

we live in a world which is continuously accommodating new and extraordinary changes. From thrilling developments in technology to the day-to-day changes we face in our personal lives.

For those on the spectrum, tolerating change (regardless of how minor) can seem excruciating and like the most daunting process imaginable. We love sticking to our routines amongst the few people we trust. We enjoy structure and the comfort of knowing exactly what each day will bring. We struggle to understand the reasons behind changes and avoid them because they often appear meaningless, especially when all seems well and life is going swimmingly and the reason for change doesn't make any sense. If everything is fine, what is the need for change?

I struggle to justify the need to do and accept things which don't always result in a black-and-white, clear outcome. It seems pointless, in the same way small talk does. I prefer knowing what will happen and when it will happen, too. I often ask myself the above question and jump to the conclusion that changes will cause nothing but trouble. My instant reaction is fear and I become agitated and stressed about the possible outcome of the change on the horizon.

I sit in a room and absorb the information around me. But without the acknowledgement that I am doing so. I have a clear understanding of the furniture placed to its exact spot and can easily detect when even the slightest of changes has occurred. Which only overflows me with confusion and an array of questions as I remain unaware of what the need for the change was.

Throughout my life I've learned that changes happen every day and it's the way we familiarise ourselves with them that matters. Realising that I have survived every change has assisted in my positive thinking and my growing willingness to take a leap into the unknown. We must forgive ourselves for becoming upset when faced with a change, because it's all part of our condition. Autism isn't a disability, but a different ability.

The ability to handle whatever life throws our way with our learned coping mechanisms to guide us through.

Change is unavoidable, as much as it pains me to say. Although scary, changes don't have to be bad and they can actually signify the beginning of something beautiful. The reason behind changes isn't always clear, which again is tricky to tolerate due to the fear of the unknown, but we can put our trust in those around us that it is for the greater good as opposed to dwelling on fears and letting high levels of anxiety kick in.

Without change, things wouldn't improve. We'd all remain in our small comfort zones, which can be beautiful places, but they can limit growth. Caterpillars transform into gorgeous butterflies, and that's the way I am learning to view the topic. We wouldn't be blessed with the magnificent things we have without having undergone scary changes. Change was crucial to move on from our historic days to a world which strives to act as a solid foundation for the lives we wish to create for ourselves and our loved ones.

For instance, my journey towards university was a daunting change to begin with where I was faced with many challenges. I tackled the move from primary school to secondary school, and then to college. So this was bound to be another success. Meeting new people, settling into my new surroundings and tackling the anxieties I held regarding meeting new friends and my new teachers. Personally, I allowed my autism to act as a stepping stone to overcoming my fears because I remained positive that it would all be worth it as I headed on my career pathway to saving animals. Nothing was going to stop me from succeeding in university life, and once I popped my positive pants on, I truly was winning!

Changes can be terrifying to cope with. But as long as we put one foot in front of the other, confide in those around us and focus on the advantages, we will be okay and alterations will become increasingly tolerable.

Laura

letters to the Editor

Dear Goth,

I loved the October issue of *the Spectrum*. The non-binary person on the cover is beautiful. I've never seen such a masculine, multi-coloured and striped lady before: her hips cannot lie! Stunning painting. Will Walki tell us if it is of Heidi?

Speaking of whom, I'm writing to you in the hope that you'll pass this letter on to Heidi, the Aspie who wrote the letter to you on page 10. My heart went out to her. Her range of sensory rubbery squidgies which she keeps in an inflatable "puffy nest" make the world more reliable for her: these are essential in the wind for long hair. As an Aspie myself with certain sensitivities and a childlike spirit, I can also understand. An extremely young looking 50, everyone thinks I'm 33! Well, apparently I used to look only half my age: so maybe I am catching up at last. Actually I study International Finance in an environment which is also peaceful, calm and non-aggressive — on the highest hill of Edinburgh. I'm okay after also struggling with being "all grownup" before I had my Aspie diagnosis three weeks ago. I started considering a vocation to become a rabbi in a niggling intermittent way, but after three decades am still considering it. I can drive and live on my own, but usually just stay at home and see no-one. I also think we Aspies are sensitive souls. Moreover, I agree that we could be having more fun than many neurotypical grownups. So, maybe I can visit that Carmelite library and read about a friar's spirituality.

Ji

PS. I'm on the way-hay!

It is not Heidi, as it was submitted several years after Heidi's letter, Editor.

Dear Goth,

I would be interested to know what you and the readers think about the use of Autistic (with the capital "a"). I have seen it used to indicate involvement with the Autistic community and Autistic culture in a similar way to the Deaf community.

I think that the Deaf community use the capital to distinguish themselves from deaf people who regard themselves as disabled and may have little contact with other Deaf/deaf people. The Deaf people see being Deaf as a difference and that the disabling aspects of deafness come from society's interactions with them. They are very involved with the Deaf community and see being Deaf as a key part of who they are. Although I do perceive myself as disabled, I think that that mostly comes from my anxiety and depression and how they interact with my Autism as well as from my interactions with society.

A friend of mine said that some people don't like the capital "a" because medical diagnoses are usually given capital letters by doctors, which I hadn't thought about. I do like the idea of being able to identify as being culturally Autistic rather than just medically autistic. I would be interested to hear other people's thoughts on this.

Laura

Dear *Asperger United*,

I just want to express my disappointment that you plan to change the name of your magazine that I have been getting since 2004.

I myself have no plans to say I no longer have Asperger's or that I am an Aspie.

Asperger syndrome may be named after someone but I see it as something in itself.

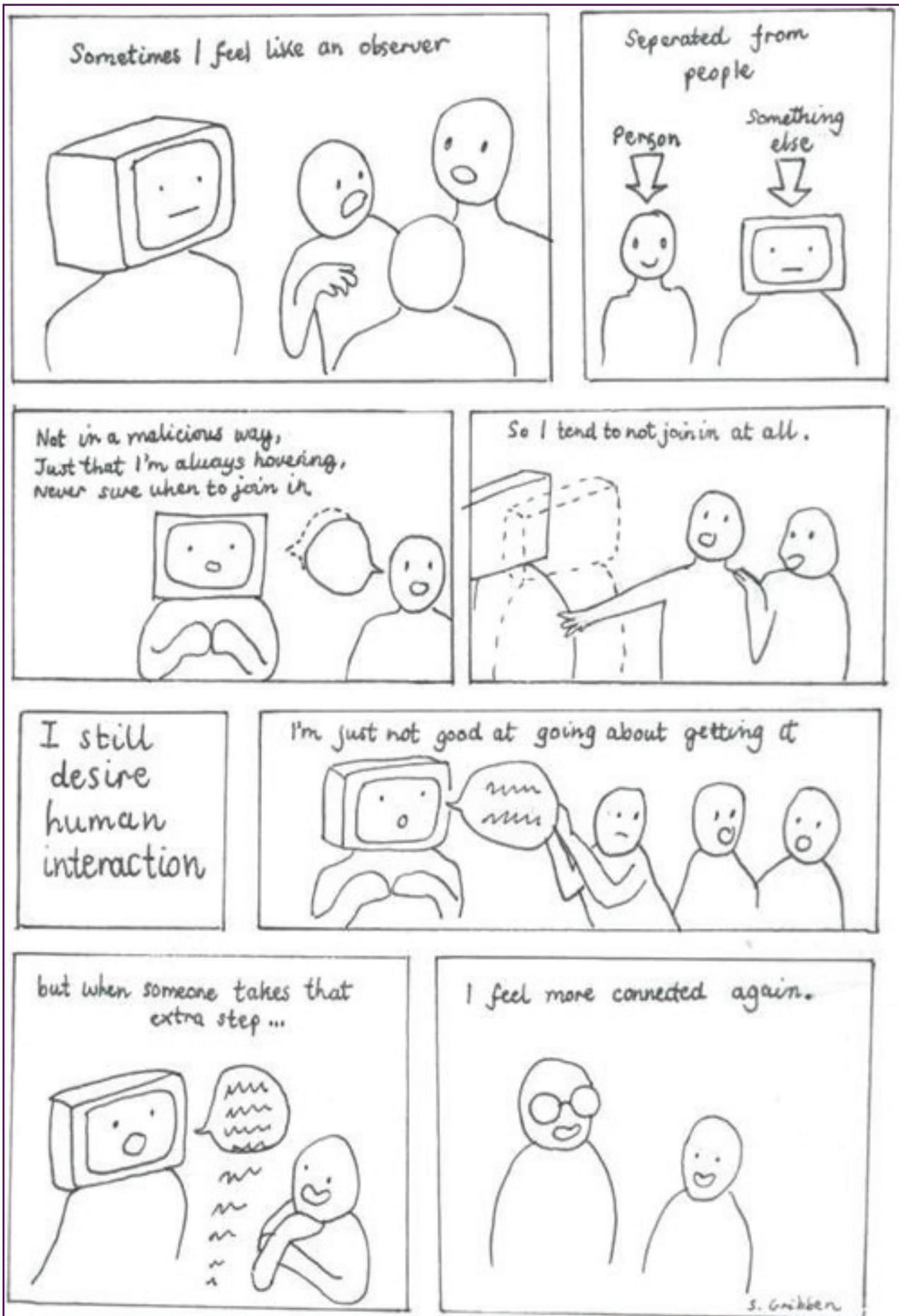
Asperger, not Asperger's syndrome, I use, as it does not belong to him: it's a shame it cannot be promoted for all the great qualities that people with Asperger syndrome have.

I have Asperger syndrome, I think you may find so do many others: I think you should ask them if they would like a change full-stop, not just for suggestions for what a new name should be — that might be an insult?

Regards,

Nicholas

Asperger's and proud!



A new therapy for people with autism

by Max

Hello everyone, my name is Max — Maximillian to those who get annoyed with me — and I'm classified as a high-functioning autistic. I am a first-year undergraduate studying for a BSc in autism. I thought — upon taking advice — I would write to *the Spectrum* to get the opinions of autistics about a new type of therapy. I believe it is a ground-breaking idea that could really help the community. It is a long way from being implemented or evidenced. At the moment it is only an idea. This is the first step in a very long road to bring a useful functional tool for therapists everywhere. If autistics like yourselves feel the idea is workable and so do professionals then that is a huge step for our community.

The therapy is called Skill Enhancement Therapy known in short as SET. The therapy strives to be 100% client-centred. It begins with identifying and understanding an autistic's obsession or obsessions, known in SET as skills. It would not be looking at transient skills — the ones that come and go — but looking at mainly root skills (root obsessions) that stay with us, that we always go back to, those that can be called long-term interests. For me, for example, it is running and politics. It is the turning of these root obsessions into lifelong interests or employment skills to give us well-rounded happy lives. This could be the key to a better experience in therapy and in life for many autistics. Sometimes therapies just do not work within the community. Instead of viewing obsessions as something inherently negative as some therapies do, I believe our intense interest in a particular thing really gives us that edge over non-autistics! We really do know everything about that one thing. That is a real skill and should be encouraged. In the therapy session the autistic will have time to talk if they just want someone to talk to — the opportunity is there, this is therapy after all (!), but the session will focus mainly on exploring

their skill (obsession). Let's say the skill is in hairdressing (a simple example). In the session there will be time to explore and develop a deeper understanding about hairdressing. If the autistic is old enough the therapist may try and see if there is any possibility to get him or her some experience working in a local salon. Skills are actualised.

The whole therapy ideology centres around the person, listening, enhancing skills, creating opportunities. The autistic client will never be pressured to do anything or say anything he or she does not feel comfortable with. They will not be expected to change or alter their behaviour or made to feel being autistic is wrong somehow. What they want to get out of the session or do in the session is up to that autistic. There is a larger picture to all of this but first I want to float the idea of creating a whole-person therapy which enhances the autistic without changing their inherent personality or gifts. Today's therapies I believe (and feel free to contradict me) seem to focus on this idea of change which I feel is wrong. We should not have to change. We are unique, and this uniqueness should be celebrated! If there is a client that has a negative skill (obsession) such as turning lights on or off, then the therapist will try and replace this with a positive skill such as operating the lights for a school production. This is not a change per se: the client still gets to switch lights on and off but it is put into a more appropriate setting. This is all hypothetical at the moment but will hopefully be a reality in the future. There have been similar ideas such as the Son-Rise Program in the United States, but this whole-person approach is a first (I believe) for our community, written and devised as it is by one of the community. I want to elicit the view of the community before moving on to the next stage of research as this therapy is for the community.

Hello,

I am attaching an article that my brother, Bruce, has just written and would like to share with others in your magazine. He is trying to understand himself, as he was diagnosed at the age of 47. I am hoping that maybe responses from others could help him be more positive about his diagnosis as he feels his life is over, but I think if he could get some support things could really look up for him.

It would be great if you could publish his “story”. I am trying to encourage him to write to others on your pen-pal page, I am hoping this will happen sometime soon.

Many thanks,

Isobel

The Asperger's syndrome victim

by Bruce

Unknown by me, I have lived with Asperger's syndrome all my life and was diagnosed last year in 2011 by a qualified professional at the age of 47.

I now know why I have been like this, now fitting into place and making partial sense, like a jigsaw puzzle, for the very first time. I now know why I was a quiet, withdrawn child who could not make sense of the human world. I know why I was terrified of absolutely everyone and the whole world felt like my enemy. I felt like an alien trapped in a human body, wanting so desperately to escape my existence.

I know why I stood in one corner of a playground and froze like a statue, terrified of being noticed by others while they all played along with their friends. Playtime was no playtime for me, but a feeling of exposure for all to see me. If a football passed by me, I'd quickly

move to avoid it, so not to be involved in what I felt was a hooligans' game. At school I was no match for anything as I was a weak, small and skinny boy with an asthmatic condition. I was ill a lot and stayed off school when I could not breathe properly. A doctor would come to my house to give me an injection to breathe easy again. I would feel my heart pumping faster as the fluid went in, but at least I could then breathe.

I did not concentrate on lessons as I could not take information in and retain it. I tried, but my then-unknown Asperger's would not allow me, and, to add to that, disrupting, misbehaving pupils and growing bullies: there was not much chance for me. I had a lot of bullies, in the end two dozen — I used to count them. I suffered intense physical pain, from the punches and kicks and bruises. 1975 to 1979 was a very different world to now, where bullying is not tolerated. Going to school the next day with bruises, then to be bruised in the same place again, still painful from the day before. It was like a planet of the evil beings. Everyone was horrible!

My brain functioned in a way that does not correspond with others' ways of thinking. How many people have been like this in life, unaware that they are different? I was informed that the most psychological damage is done when the victim cannot understand why he or she is being bullied. This was my case — I never understood why! So I alienate people, and they alienate me as “odd” or “different”. This is what brought about my bullies: Asperger's syndrome and asthma.

I paid more attention in school to the trains passing my classroom window. I could see a railway station nearby. Every time I was in school (not everyday) I would watch the trains speed into the station. I'd watch people on the platforms, count how many there were waiting for a train. The trains were every eight minutes. I would count how many carriages, watch the guard open and close doors, imagine I was a passenger getting on it, right there on the platform and travelling on it as it moved off, seeing what they might be seeing. I knew a lot about trains, different styles, sounds, looks. A daydreamer, I was.

an article (continued)

Inevitably, truanting came into being, simply because I had too much physical assault and too many bullies. I was too terrified to explain my sufferings to anyone, even my mum or dad, because of repercussions — in case the bullies found out and got me even more. Truanting and Asperger's syndrome have moulded my life forever. I have been truanting or avoiding everything, ever since I was young.

I am alive today, writing this because I have saved my life, my own way, truanting and avoiding. Truanting became a thrilling part of my life, exploring different London locations on different days, usually by bus. I would pretend to go to school as usual, and then before reaching the school gates, not go in and instead, proceed to the nearest bus stop. I'd get on a bus and travel for 5p up to its destination, get off and walk the streets, which were places full of shops. It would be a very long day, alone. I went to toy shops I used to be familiar with and sometimes buy a few joke novelties. I'd then walk to the nearest parks and hang round the swings and roundabouts. I was still always in my school uniform, but unaware that I was, and always alone. It's amazing how nobody reported me, a lone kid in a play park on a school day! However, at that time, I never felt lonely because of escaping bullies and physical and emotional pain. It instead was a feeling of freedom, and was also very exciting when truanting. Time took its time, when looking at my watch as I would daydream while on a swing. Eventually the time came round to leaving the park and make my way back to the bus stop and make my way home, carefully judging the time it would take to get back home to make it in time for when school was out. Of course, making it look like I had gone to school to my family, when I certainly had not. I kept this secret well. None of this, I realise today as I write this, was my fault. It was a system that let me down. However, guilt gradually set in, making me feel sad for what I was doing. Wishing I could say sorry for deceiving my family, though I felt I had no choice at the time. One thing led to another: not going to school meant I had to make up forged letters to the class teacher, pretending it was from my mum, and then to think what to

write was a problem, which I always eventually won through. I felt like I was having to lie endlessly, just to save my life from torture. I'm sure my Asperger's helped me through this as, in the end, this routine, being difficult, became easier and easier and I became an expert at wriggling my way through loopholes and never got caught. Yes, this routine was very often.

I've never been able to make friends in my life. Whenever I try, I get into some sort of unjust trouble. I had no school friends, boys or girls, in any year, ever. No teenage friends as a teenager and no adult friends. Asperger's syndrome has denied me a social life completely. It's agony for me, when I notice on the streets a group of teenagers, in the sense that I don't know what that's like. To be with a group of friends and share each other's interests. It's torture to know this is my only life, running out of time, and to be socially starved of everything good that life has on offer. I can only go as far as imagining what it is like to socialise. I can never penetrate that socialised world that everyone else makes look so easy. It is the most difficult thing in my life to accomplish. How is it done? I prefer to ride my bike, or go for long and peaceful country walks for four or five hours which eliminates all my painful, longing emotions.

Recently, I amazingly met a woman who I thought was going to be my friend. She appeared interested in me at first, as we went out to a café together, she visited my home and I her home, we walked in a park, she held my hand and even gave me a kiss. Two days later she didn't want to know me any more. What was it that put her off me? I kept calling on the phone and she kept on making up excuses to avoid me. Was it something I said that put her off me: Asperger's syndrome? A mystery! The worst thing was not the leaving but my mind thinking I've now got security of some kind, and then I haven't. Like a dream I thought was coming true, and then it did not. I felt abandoned, again. And the rope was starting to climb, got cut loose, and there I am, right back in the jungle again, lost and lonely. What is it like to have a girlfriend? This abandoned shock jolted me on a wild goose chase, chatting

to women everywhere in the hope of finding myself a partner, and it landed me in a police cell. I'll explain why. In November, I had an idea of giving Christmas cards to retailers in shops. Being Asperger's, my personality has been very naïve, not to say that all who have Asperger's are, and I did not know of repercussions, or did not think ahead of what might happen. So I gave out cards to various women in shops at the till wishing them a happy Christmas. A sweet little pink card with a kitten on the card cover with a polite message inside reading "Happy Christmas to a beautiful woman". My idea was so that they remember me in a positive way. Obviously this was not to be. I was in a then very happy state of mind, so I thought I would be spreading my happiness. Not so. Several women complained about me, and I was arrested and put into a police cell. I was asked by the police, "Was I aware that I could be putting fear into the women by giving them Christmas cards over the counter?" I said "Not at all." And all this came to me as a big shock. So, once again, instead of me making friends, I made enemies. My Asperger's probably to blame. As a person I'm quiet, withdrawn, and shy, so I thought how did this freak them out! I did not understand.

Amazingly, I've been tied up and gagged, knocked unconscious, been beaten, punched, mugged, traumatised loads and arrested for being warm-natured, gentle and inoffensive. Loneliness has followed me my entire life! I am abandoned from society. I guess society will only respect me if I'm walking down a street with the "correct"-aged woman on my arm, and if they don't detect my Asperger's. They all see lone innocent men as threats: I've even had death threats sent by text.

The world of the human race and our rules and regulations of our modern era are difficult for the Asperger's sufferer, and for myself, it has always been beyond difficult. Everything is hard for everyone, so how much harder is it for someone living with Asperger's?

It is vital that children socialise young at school, where friends usually begin, so that they can carry on progressing with confidence.

Asperger's syndrome stopped this from happening in my life; it never happened. How unaware I was of the multitude of suffering that lay ahead in the future for me. The vulnerability in me that created a target for bullies.

If one is successful, they just happen to be lucky, like the lottery. If one is unsuccessful, they just happen to be unlucky, like someone who is killed in a plane crash. Lucky for some has always been. Unlucky for some has always been. Life is not fair for me, as with some others. My diagnosed Asperger's syndrome has destroyed my life.

I have always been tidy, have had a tidy room and love discipline and order. This is maybe why I like trains so much. There is a perfection in their running along a perfect track of iron rails to which there is perfect control. Straight, balanced and smooth. I am an artist and I love perfection. Something my life has never been: perfect!

How quickly the chances of marriage, children and being a dad diminish. My chances are gone, a wish I will now carry to my grave. If I could have my chances again, and to be born in a normal condition, more positive and extroverted, I could then find out what a real life would have felt like. I deserved a normal life too, like others, but did not get, because of my condition, so I missed life. And instead of the respect that I so much deserved as an Asperger's syndrome person needs, I received misunderstanding and hostility.

It's an ignorant society that labels itself modern, but underneath all that "glitzy glamour" they are all still very primal minds that never learn anything that's outside of their narrow vision, as in historical times. They might find something wrong in us, but we can all see the defects in the rest of them, so-called normal people . . .

What you see on the outside of me isn't true — but what you don't see on the hidden side is the truth.

(We all unite and bond as one happy family.)

Getting to the heart of the head – my experience in using CBD oil for mental well-being

by Virginia

The last five years have been an enlightening personal journey. I qualified as an English Teacher in 1997 and after some trial runs in schools which did not quite tick every box as “correct”, following the birth of my son, I settled into a comfortable niche at a local independent school. I worked; it worked. The school run belonged to both of us, rolling up to our respective positions within the educational establishment every morning for twelve years. Our coinciding holidays avoided the clash of work and home that often offers a Hobson’s choice for the working mum, torn between child and career. Sounds idyllic doesn’t it?

Yet in reality, even disregarding the sheer mountain of preparation and marking that comes as a teacher’s inevitable burden, even disregarding the indisputable fact that, no, the long summer holidays do *not* compensate for the exhaustive onslaught known as “the teaching term”, things were far from easy.

Despite being a high achiever academically, for my whole working life I had struggled. At school, I struggled socially, but found my comfort zone with peers and projects. At work, however, I could never decipher the rules. Others seemed to pick up cues effortlessly, able to multi-task, process information, remember to-do lists and laugh along with colleagues. For me, it was always an extra effort. I practised conversations in the mirror, I rehearsed religiously for scenarios that might occur, where I now realise others simply improvised. I could think on my feet in lessons; I fell down over staffroom politics. Once, when I was asked to take the minutes of a meeting, I slavishly transcribed every single word, not realising that some of the “banter” needed editing to avoid the swift dismissal of the head of department. The minutes were retrieved from pigeon-holes in the nick of time, thus

avoiding his embarrassment, but precipitating mine, and banishing me to the loo with a massive meltdown. Another time I started a panic about a pandemic when, after a little cough, I made a quip about my cousin visiting with bird flu. Not so funny when the next day the Headmaster hauled me into his office, as a parent had telephoned to berate him about endangering the children! I could go on with a list of workplace faux pas, but they are ignominiously numerous.

The point in revealing my ineptitude will shortly become clear. Until 2013, I soldiered on, a strange dichotomy of all-star results but with my foot firmly in my mouth, and my desk looking like an explosion had happened. Every day I smiled serenely to mask the storm inside. Every day I had blurred vision, headaches, crippling stomach pain, and although I floated along the corridors in co-ordinated clothing, I felt somehow displaced, surreally hovering a few inches above the floor. When I read texts out loud, the words blurred and changed shape, dropping off the page. I survived on painkillers and diet fizz to combat the agony and perpetual fatigue. Soon I would reach crisis point.

Suffering from stress, I left school in 2013 to fly solo as a private tutor. Even I was surprised by my rapid success, moving quickly from three students per week to twenty-eight regulars. Yes, it meant a lot of hard work, as well as hours where I commenced the majority of my work just as others were winding down in the evenings. However, I absolutely loved it.

My moment of epiphany arrived when I took on a home-school student with Asperger’s syndrome. It was like looking in a mirror and it slowly dawned on me that this might be the reason for many of my own struggles. A professional confirmed the suspicion for me, and

a visit to the optician's also confirmed that I had Irlen's syndrome — a scotopic sensitivity and perceptual processing disorder. Things began to fall into place.

But despite feeling less stressed in the workplace, I still suffered from panic attacks and depression. Even though my work was essentially my hobby, I was forever fully wound; often wide awake when I should be sleeping. I still suffered crippling pain on occasion (I also discovered a gluten and wheat intolerance). I still used painkillers and a cocktail of sleeping aids. Was there anything that could take away the constant feeling of being overwhelmed by life? Would anything be able to rein in my fuzzy buzzy brain?

In despair, I turned to an internet support group for women with autism. Regular chats gave good advice and re-assurance, and I was persuaded to try CBD oil at the suggestion of one of the women. I began by taking five small drops a day, under the tongue, and then increased to five in the morning and five at night. After two to three weeks, I began to feel the benefits.

CBD is a cannabinoid, and is derived from the cannabis plant. But before you question the legality and ethics of this, I can assure you it is legal and available in the high street. I buy mine from a health-food store. This is because it does not contain THC (tetrahydrocannabinol), the psychoactive ingredient that gets the marijuana user "high." There have been some reports of CBD oil causing users to fail drug tests, but this is likely either a rumour, or they are buying their substance from less-than-reputable suppliers. Growing scientific evidence suggests it is highly beneficial in some key areas: relieving pain¹, reducing anxiety and depression², alleviating cancer-related symptoms³ including those caused by treatment⁴, and reducing acne⁵. Studies also show that it might have neuroprotective properties (it has improved symptoms in those with epilepsy⁶ and Parkinson's⁷ for instance). Furthermore, it may help with heart health⁸, and though more studies are needed, it may help with substance abuse disorder⁹, diabetes prevention¹⁰, tumours¹¹ and even have anti-psychotic effects¹².

Of course, for some there may be unpleasant side-effects, because everyone is different, and there are still some questions to be considered in the medical industry about its efficacy and safety. But for me it is unquestionably successful in reducing anxiety and providing a sense of well-being that I can honestly say I have never really experienced before. My head is calmer, I am not suffering from regular panic attacks and I feel able to prioritise tasks more easily. Most importantly, I am relieved from oppressive moods which could be very debilitating when they struck. I can't tell you that it is definitely the result of CBD oil alone, or whether the improvement is simply a co-incidence, but I can tell you that there is an improvement and I have had no ill-effects. It isn't that costly, although to me there is no price on peace of mind. It doesn't get me high, but, hey, you can't have everything can you?

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two letters and a poem

A letter about a book

from **Anne-Laure**

I have not contributed in a while but here is something I would like to share with readers of *the Spectrum*. By the way, I love the new name.

I recently wrote a little book about who I am, entitled *The joy of abnormality*. I am not telling you about it to increase my sales figures but because of the effect it has had on others, and on myself.

Family, friends and even colleagues are starting to talk about Asperger's, both with me and around me. I received a few emails thanking me for writing and sharing my story, from readers who could understand things about themselves for the first time. This drove me to tears more often than not but knowing the journey of discovery will be easier for some because I wrote about my own is worth the pain a thousand times over.

So this is my message to you: speak up. Speak up! Too many of us find out about our difference too late in life, after too many setbacks.

Find happiness in being who you are. And help others along the way, because we are still *united*.

New cover colour

notice by **the Goth**

From April, edition 98, the title on the cover, called the masthead of the magazine, will change from black lettering to the new purple lettering — the same colour as this notice and all the other purple text in the magazine.

I think this will be the last change for the new brand. I hope you like the change, and of course let me know what you think.

Hello NAS,

a question about the Manchester Student Union replacing clapping with waving was asked on *Question time*.

I quote from *Question time* panel-member George Mpanga, “It is not fair to just laugh down difference”. Even though George and another panel member (Emily Thornberry MP) explained that some individuals like some on the autistic spectrum are sensitive to noise (for example clapping) this difference was de facto laughed at by the other three panel members (Claude Littner, Isabel Oakeshott and David Gauke MP) and the chairman David Dimbleby and many members of the *Question time* audience.

Has the NAS viewed this programme (if not, please do so)? Has/Will the NAS made/make any representation to the BBC and/or to those who took part in the programme?

I am on the autistic spectrum but I do not have this auditory difference. However . . .

Michael



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.
- 2) *The Spectrum* is quarterly, published in January, April, July and October. If you do not receive a copy when you expect to, please contact the magazine.
- 3) Pieces that appear in *the Spectrum* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 4) *The Spectrum* administers the copyright of everything that appears and it does this on behalf of the authors.
- 5) The NAS plans to expand *the Spectrum*'s presence on social media, so if you don't want your contribution used in this way, please make that clear when you submit it.
- 6) The NAS would like to keep in touch with you about NAS services, support, events, campaigns and fundraising. If you want to hear from the NAS, you can opt in to this on the NAS website. The NAS will only contact you in the ways you want.
- 7) If you subscribe to the paper edition and move house, please inform *the Spectrum* and include your old address as well as your new address. Even if you've paid for the Royal Mail forwarding service (or another forwarding service), you still need to inform *the Spectrum* that you have moved address.
- 8) You do not have to be a member of the NAS to subscribe to *the Spectrum*.
- 9) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as the line isn't very clear. Please give any phone number you leave twice for the same reason. Remember to give your postal address so that we can find your record.
- 10) You can sign up for an email notifying you whenever a new edition of *the Spectrum* is posted on the webpage above. Email **the.Spectrum@nas.org.uk** asking for the notification by email and please include your full name, postcode and let us know whether you want to subscribe to the the paid paper edition too.
- 11) If you want to unsubscribe from the paper version, inform *the Spectrum* and include your postal address. Or to unsubscribe from the email notification, include your email address.
- 12) If you want to resubscribe (or subscribe for the first time) inform *the Spectrum* and include your postal address and fee (for the paper version) or email address (for the email notification).
- 13) Book reviews are the most popular thing with readers of *the Spectrum*, so please consider submitting one. They can be about any book, not just books about autism. Also, they do not have to be short (the Goth keeps most of his reviews short to leave more space for other writers). If you do not want your review to appear in other NAS publicity about that book, please make this clear.
- 14) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.

Spring!

by Tony

I've noticed (and made the connection this year) between certain symptoms I've been getting for decades that others also seem to get, but without the insight I seem to have. For instance, I have very itchy skin at the moment, which seemed to start at the hips and buttocks and moved down to the shins and now my ankles. I've heard people complain that they think this is down to their washing powder and sensitivity to it in some people more than others (those on the autistic spectrum and possibly others, for instance).

I also noticed with the advent of spring that certain aches and pains have resurfaced, similar to those described by people who claim to be able to tell a change in the weather for the worse (atmospheric pressure? Change in dampness amount in the air?). Coupled with this, I noted a feeling of frustration with my body (sloth?) and increased production in the ones-and-twos department, culminating in release of this and return to normal flow, topped with a

migraine (damming of energy/material as with frozen river and spring melt): I've suffered with these headaches for years but never until now associated them with the seasons.

All of this I think indicates that the bodies of humans and animals react to climate change, in the same way that plants do. The latter can't tell us why they are reacting as they do or even what they are reacting to but maybe our reactions can tell us what is going on with them too. I remember a weatherman on TV saying that the animals had been caught out one year, by a sudden unexpected flurry of snow, whereas I believe that they were reacting to the lengthening of the days (as plants do) and not the cold spell. Maybe this explains depression (SAD — seasonal affective disorder) and wanting to go to bed all the time as opposed to insomnia (snp rising) and unexpected urge to wake up and stay awake?

Has anybody else noticed this?

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