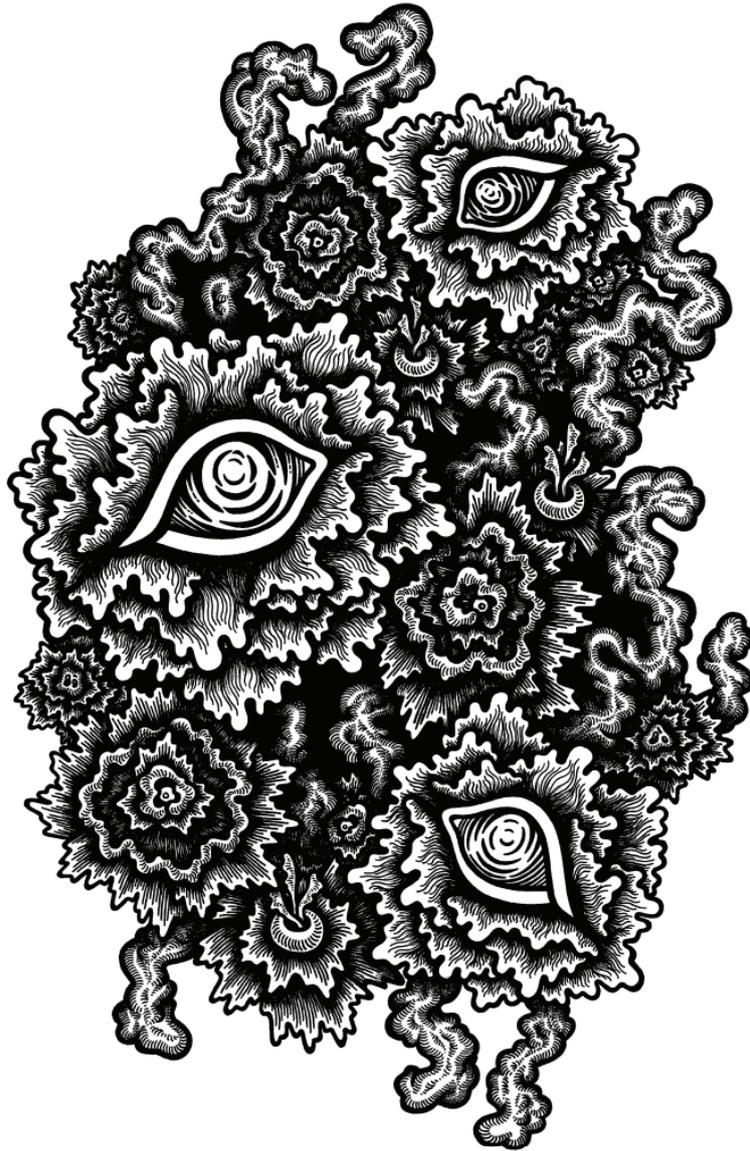


Produced by and for Autistic people

The *Spectrum*

Edition **104** October 2020



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.

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This magazine was founded as *Asperger United* in 1993 by Pamela Yates and Patricia Howlin, in association with the Maudsley Hospital, and Mark Bebbington and Judy Lynch of the National Autistic Society.

This was in response to a recognised dearth of services for people with Asperger syndrome and the potential for self-help and networking as a means of support for this group.

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds, John Joyce and the current editor, the Goth (who does not wear black).

Pamela Yates provided support and advice to the editors until the publication was handed over to the National Autistic Society in 2000.

The name *Asperger United* was chosen by the group of original readers as the most "appropriate name" for the publication. This was suggested by Anna Kaczynski. The name *the Spectrum* was suggested by dozens of people and chosen in an online poll in 2018.

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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 **9 November 2020**

Welcome to the October edition of *the Spectrum*.

It's possible that all aspects of the lockdown will have been lifted by the time you read this, but while I am writing, things are still fairly restricted around me.

Most — perhaps all — of us have had difficulty coping with the lockdown: this was evident from the very stressed submissions I received for the July edition, but I am pleased to see that some much brighter pieces were again being submitted for the October issue.

I also noticed that more long pieces (more time at home?), more art, and more poetry

(needing an outlet for feelings?) have been submitted since the pandemic hit. And more nostalgic pieces, such as appears on the back page here.

Face masks are clearly a problem for many people with anxiety, whether or not they are Autistic, so do let me know about any coping strategies you use. As I mention on page 10, it is likely to be a year or more before a stable “new normal” develops. In the mean time I will continue to struggle to buy everything I need in just one shop a week, how about you?

Yours,

the Editor

the lockdown edition — suggestion for next issue on page 9

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What do you see in a cloud?

by **The Pixidustlady**

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Change is the only true constant in life. Recently, two innocuous, unrelated things happened to me on the same day. They collided in my mind, creating a cusp that I'm now teetering on the edge of. A cloud and a questionnaire have forced me to reconsider how I define myself as a person. I've tried to record my experience of this change in the hope it might help me connect with you now.

Four years ago, when I got my Asperger's diagnosis, it felt like the conclusion of a lifelong quest: I'd always known I was different, and now I knew why. I had my answer, my reason. I was relieved, but also afraid. I didn't see myself as disabled at all, but I knew people without experience or understanding might see Asperger's as a label and make assumptions.

At the time I made only one change: I moved from crowded London back to rural Scotland to be near family. This simplified life, but otherwise, I carried on as normal. I tried different things for work, short-term temporary contracts, before landing a dream job I thought I'd keep until retirement, in a local

charity shop. I loved it, and really invested in my new life: things were going really well. Until it all changed.

Head office brought in a new retail manager. There was all sorts of extra paperwork. New competition opened up next door, affecting donations and takings. Within three months I'd lost all my autonomy and was under constant pressure to increase sales. I got stressed, flustered and short-tempered. I couldn't sleep, compounding my constant worries. I felt like I was drowning, trying to keep up with everything and everyone. I hated myself for failing. My mind was chaotic: I was on edge all the time. The tiniest problems would reduce me to floods of tears. In the end I was completely overwhelmed and just shut down: locking my door, turning off my 'phone and hiding from the world in bed.

The doctor signed me off for three weeks with anxiety and doubled my medication to help me sleep. I had calmed down, but all my joy and enthusiasm was gone. When I went back to work, head office insisted on an occupational health assessment

and then proceeded to ignore all the recommendations that were made. I carried on for a while, but it was obvious they wanted me out, so I handed in my notice. I'd lasted nineteen months, which was actually a personal best for me.

After six months off my savings have run out: I'm re-entering the workforce. I like work. It's good to be busy and feel useful. But my new job comes with a lot of paperwork, contracts and proof of my eligibility to work in the UK. There's also a medical questionnaire for HR. It feels intensely invasive, but I answer with my usual candour. Then I reach a section about disability. I'm struck by two questions: "Are you registered disabled?" and "Do you consider yourself disabled?" Both questions deal with one issue, but they approach it from different perspectives. The first asks how society sees you: an external view. The second asks how you see yourself: an internal view. Like the two faces of a coin, these two perspectives are inextricably attached, yet opposite at the same time.

"You're disabled under the *Equality Act 2010* if you have a

physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities.”

Reading this definition planted a seed of doubt in my mind. I begin to question my definitions. Could my being unable to maintain regular employment without succumbing to crippling stress be classed as a “substantial negative effect”? My propensity to dissolve into tears as a coping mechanism has always become an issue in every job, no matter how hard I work to make up for it. Persistent emotional breakdowns due to stress have become “normal” for me over the last twenty-five years. The older I get, the more “long-term” this situation becomes. I’m suddenly confronted by the fact that my “normal” doesn’t match most other people’s. Could there be a possibility that, by this definition, wider society might class my experience of Asperger’s as a “disability”? Could they be right?

The only reason I was even entertaining these notions was the riddle of a cloud I’d solved a few hours earlier. Living on the edge of the Atlantic means I’ve experienced some serious weather: the wind here can be *epic*. Growing up in this environment nurtured my love for endless skies and vast cloudscapes. Later, years of city living dampened my appreciation. With only narrow

strips of sky, clouds became unremarkable; just scudding between buildings, like a TV on in the background while you do something else. Until that morning.

I’d sat down in my armchair to drink my morning coffee. Directly in my eye-line, framed by the central section of my window, was a beautiful great cloud. I could only stare. The longer I did, the more the bright sunshine illuminated every detail of its boundary in space. A heap of bulbous billows seemed to emerge from the cloud’s fluffier, wide-set base, captured like the beginning of an explosive dust cloud frozen in time. Different shades of white and grey resolved to purples and yellows before my eyes as I studied its textured surface.

Most striking, however, was its absolute stillness. It was as though it had been painted straight onto the glass, to be curated into this sublime gallery experience, especially for me. I couldn’t look hard enough as my gaze was transformed into that of a great painter: I could feel a work of art straining to burst forth from my talentless heart. The cloud almost filled the restricted field of the frame, hanging so utterly motionless it began to seem solid, and immovable. The inert crispness of its distinct form gave it an uncanny weightiness, even as my mind told me it was just water vapour. I was enchanted.

Fluttering leaves in the foreground of my garden broke the spell. There was wind, which ignited my curiosity: how could the cloud be so still in the presence of a breeze? I simply had to reconcile this question: I’m compelled to figure out how things work in order to feel satisfied and calm. I needed more information, more clues to solve this mystery. I wanted a better view of my cloud in its wider context.

My usual walk takes me down to the beach, but this time I turned the other way. I climbed to the crest of the hill, revealing my favourite vista. I could see our house nestled amongst its trees in the village, the beach curving below, the sea and more islands beyond, hazily stretching all the way to the horizon. The landscape was lush: green fields, hills purple with heather, the sea a deep blue. The white sand of the beach was marked by tide lines of black seaweed. Wind turbines were spinning; a red tractor ploughed in the fields. Grey stone houses punctuated the landscape, with the occasional window reflecting a flash of sun.

From my lofty vantage point, right up under the flat bases of the clouds, their shadows were clearly visible across this familiar patchwork. My cloud still hung like a crisp meringue in the uninterrupted expanse of the sky. I could hear the birds chattering their songs, a bumblebee buzzing about his business with the

feature (continued)

dandelions, the slow steady whirring of more windmills turning behind me. The Sun's warmth and this soft drone of life soothed me into a state of meditative contemplation. My cloud seemed to loom large over me. The threshold of its shadow had advanced across the landscape. Thus, the penny dropped!

I had been facing into the lightest, gentlest wind the whole time: the cloud was moving directly toward me. This fluke of trajectory had disguised its stately progress through the sky. My relief was instant and palpable. Trust in my own senses was restored. A single cloud had shown me that only by changing my perspective and taking the time to really observe life was I able to solve the riddle of its imperceptible movement.

This lesson was still fresh in my mind as I came to fill in the medical questionnaire later that day. I didn't expect to find an existential crisis in some routine paperwork, but the cloud and the combination of the two questions met in my mind and got me thinking. That cloud was a metaphor for me, for my life. Internally, living with Asperger's is like existing inside a cloud. Everyone and everything they do is confusing, I'm totally surrounded, without any reference points, or anything to anchor to. I'm lost in my own grey fog, with no idea where my boundaries are, or what shape I am.

From an external perspective though, other people have a clear view of me. They can see I have a distinct form and plenty of edges. They can see me coming. My presence sometimes casts a shadow and leaves them cold. Sometimes I can blot out their sunshine with my grey mood. Sometimes I can be thunderous and stop a heart with one bolt of lightning. Sometimes I blanket them in a thick layer of frost and snow so my heart can hibernate beneath, just to survive. Eventually, I rain tears over everything to relieve the pressure that has built up inside me. Neurotypical people have a way to describe people like me that makes sense only to them: mentally disabled.

I'm not here to argue for or against whether their label is fair or accurate. But if they're going to make me tick a box and choose, just so that they can feel more comfortable, maybe there's something in it for me. By realising there's a stark difference between how I see myself and how others see me, I've discovered that my diagnosis is not the ending I thought it was. It turns out I didn't complete a race: it was just the first stage of a triathlon. I became so good at performing "normal" for everyone else, masking my true self, that I tricked myself into believing it was true. Work has always proved it's impossible for me to maintain that façade permanently: I've

never managed it yet, so maybe now it's time to admit I never will.

I see now that the potential ramifications of my diagnosis have been gradually moving towards me for a long time, looming ever larger in my consciousness. Maybe it's time to make a real change. Maybe I'm ready to see myself from an external perspective, just like I saw that cloud. Maybe it's time to define myself in a way other people can recognise and understand by accepting a label I wouldn't choose for myself. Maybe acknowledging the reality of how people perceive me from a neurotypical perspective will turn out to be the key to striking a balance between my internal and external struggles, as I continue trying to connect with people and participate in life.

The concept of synchronicity allows for people to find meaning by connecting random events. Seeing that cloud on the same day I read those two questions was just a coincidence. But it was my Asperger's brain that linked the two things in such a way as to find a valuable insight in their combination. Adopting a label and admitting I need help to function in a society geared towards neurotypical minds is not me moving into what some might consider the shadow of disability. This change is me stepping out into the light so everyone can see who I really am, and all the beauty I hold within my form.

Pen pals

Pen pal number 321

Hi everyone, my name is Brandon.

I am 21 years old. I was diagnosed with autism when I was 5 years old.

I am currently doing an apprenticeship at LearnPlay Foundation, in media.

My interests are going to the cinema, watching films, playing video games, going on my computer and spending time with my family.

Thank you for reading this and I hope to hear from you.

Pen pal number 322

Hi, my name is Martha, I'm 20 and I've been diagnosed with Asperger's recently.

I'm interested in science, particularly biology and specifically ecology. I love animals and have three dogs, two tortoises and a fish tank.

I love animated shows and movies, particularly stop-motion animation and cartoons. I also like to collect antiques and interesting vintage things, and I'm currently at university.

Contact me if you'd like to talk!

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

How to place a pen-pal advert

- All you need to do is send your advert along with your name and address (and email address if you want) to this magazine. You can use the Royal Mail or email. The next pen-pal number will be given to your advert when it arrives.
- Please note that this magazine does not print dating adverts, as it is unable to provide suitable support.
- Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in this magazine.
- If you get no replies, please don't take this personally.

How to reply to pen pals

- Please remember to let us know the name and number of the person whom your letter is for. (All pen pals are numbered by the editor, not the person who sends in the advert.)
- Please remember to put your address on your letter.
- To contact a pen pal, please send your letter to the Goth, c/o The National Autistic Society, 393 City Road, London, EC1V 1NG, or email the.Spectrum@nas.org.uk
- We will pass your letter on to the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.
- Please note that all pen-pal letters sent via this magazine are opened before being passed on.

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

This magazine is happy to publish pen-pal advertisements but we must stress that we are not a pen-pal or introduction organisation. We do not match people up and we cannot monitor letters (other than the first letter, that is sent via us) so please be cautious when releasing personal details in your letters. The National Autistic Society / *the Spectrum* cannot intervene or be held responsible for any ensuing correspondence between letter-writers.

Pen pal number 323

I'm Adeinne, 28 years old with Asperger syndrome from Scotland and am hoping by placing this advert in *the Spectrum* that somebody will have similar interests as myself, then hopefully they will reply then we can hopefully form a friendship which would be lovely, especially as I find it challenging to make friends and I don't mean to be rude or that but I think I would prefer email rather than letters.

My interests range from watching TV — especially quiz shows, *the Simpsons*, documentaries, crime/police/ambulance shows, and I enjoy watching *Hollyoaks* too. I also have a huge passion for animals, as they are such great creatures, so I enjoy spending time with them or just watching a cat or even just birds from the window. I enjoy watching videos on YouTube, which I do nearly every day, as I probably spend way too much time on the Internet in general but it is something I enjoy. I enjoy playing video games too on my Nintendo Switch and Playstation 4 consoles, especially racing games, Mario games, *Overcooked 2*, puzzle games or just even *the Sims 4*, which I play on my computer. I really enjoy adult colouring books, as I find it very relaxing to do, although I do want to try adult dot-to-dot books too as I haven't done a dot-to-dot puzzle in years. I enjoy puzzles from a simple word-search, crossword or a simple word game I can play on my computer. One of my big passions is going to the theatre, where I've seen some amazing shows, such as *Hairspray*, *Joseph and the amazing Technicolor dreamcoat*, *Cats*, *We will rock you* and *Annie*. I enjoy Disney as well, from collecting the merchandise to visiting the theme parks or just watching a movie, of which my current favourite has to be *Toy story 4* that I saw in the cinema.

Thank you and have a lovely day.

Pen pal number 324

Hello! I'm Lisa! I am from Wales and I have autism.

I see the world in colour, from touch to sounds to tastes, and especially music. Every letter and word has a colour. I can never get away from it. It's called synaesthesia, a "disorder". I don't like to think of it as a disorder: autism isn't a disorder either. That's just what they call people they don't understand. It makes it hard for me to learn because I think differently and I have to unjumble patterns and colours in my head to make sense when I speak, which can make me appear slow when I actually think very fast. Memories and smells are in colour too, and when the patterns and colours don't make sense I can have sudden mood changes until it's right in my head again. I can get so angry or so, so sad because of it and it's destroying my life because people don't understand and think it's aimed towards them. But this is something I could never just explain to someone so quickly as I'm still trying to understand it myself.

Basically I'm looking for someone else who has synaesthesia and how they manage daily life, as I find it quite a struggle sometimes. And incredibly lonely. Because I've never been able to just talk to someone that understands why I feel blue with purple stripes or why someone's voice is in E♭ major. I just want someone that understands and won't dismiss me like everyone else does just because I'm different. I wish more than anything that I wasn't, but I am, and I'm happy. I would love to make friends with anyone really. I hope this doesn't sound desperate — I'm actually usually a happy, bouncy person! It's just that I've recently been told that I have autism, although not properly diagnosed yet as I have been on a waiting list since I was 11 and it's made such a difference and makes so much sense. (Like my hypersensitivity to things.) I would love to find someone like me.

I love music, and I play piano. It's all so colourful and how the notes blend together, it's like painting! I love to read and am currently rereading the *His dark materials* trilogy. Spongebob was my childhood, haha. I love nature and the outdoors, and animals! I love animals — I guess that's why I'm studying zoology! I'm at university now, and just getting used to it, although it's hard.

I would love to hear from someone!

To mask or not to mask . . . that is the question!

by **Kayleigh**

For the disabled community there are many continuing problems with the pandemic, even as lockdown lifts. The one I wanted to talk about today is masks.

Masks for me are a nightmare: they give me sensory overload, panic attacks, communication struggles, and depth-perception problems. It just isn't working out. I work in a Post Office, so it has been quite controversial; I also take a train to work, which is double trouble. I also can't wear visors for almost all the same reasons.

For any of you that have the same sense of distress over it as I do, please check out Hidden Disability website, they have some lanyards that are nationally recognised so you don't have to disclose your disability all of the time.

It is frustrating and it feels very ableist when you are questioned about why you aren't wearing a mask because for most of us it isn't obvious from the outside and I am also finding that, as an Autistic person, it is extremely difficult to explain as I get easily overwhelmed and become mute at times. Especially as people ask in a very invasive and judgemental way. I have found that people don't believe Autism is a disability and is a valid reason to not wear one. I have received comments from people complaining that they "don't like" wearing them either so why should they have to and not the disabled community. Which just brings a whole new level to ableism and frankly it is exhausting trying to educate everyone.

I feel as though we are given a lose-lose decision to make: either we don't wear a mask and receive disgusted looks, judgement and ableist comments, or, we wear a mask and feel uncomfortable, distressed and overwhelmed just for the sake of avoiding the first choice. (This can apply to both physical mask wearing and metaphorical masks, both of which can be awful experiences for a lot of us!)

Initially I did try wearing a mask, only on the train to and from work but I decided it wasn't worth the distress and implications, especially as we are exempt due to government guidelines. I have had to face a lot of challenges with people judging me for it. Some don't think I'm disabled enough; some don't think it's fair that they have to, and I don't; some think I am risking everyone else and should be forced to. Why should I wear a mask on top of my metaphorical one when that already causes me so much distress that I can't cope with it?

Maybe try and contact the NAS Helpline for advice — it is natural to feel anxious and conflicted about this topic. We are all in this together, we all understand the struggles you face with this and are here for you. I hope that those strong, brave, influential Autistics (and anyone else that supports us) will stand up with us and help spread the word that we are not like others, the playing field is not even, and we need extra support and accommodations to march through life at a similar pace to everyone else. Stay safe out there.

If sufficient material is sent in, the theme for January will be **the new normal, after the pandemic**. Vote with your contributions: the more submissions on a subject sent in (from different people) the more likely that that subject

will be the theme. Writing on any subject is still welcome as are ideas for new themes, and artwork. Remember, if you want to see different content in *the Spectrum*, the best way to change it is to send something in!

letters to the Editor

Hello Goth,

please find below thoughts on the coronavirus and a thought (partly) in response to Lauren (from the previous issue).

It doesn't seem to me that the coronavirus crisis is over: the number of infections and hospitalisations will likely continue to fluctuate, creating a state of uncertainty that the whole world is now feeling. In a sense everyone else is experiencing what it is like to be autistic in a "normal" world. Unfortunately the uncertainty (and sometimes confusing rules and regulations) affect us even more — well, me anyway.

Where would we want to be in a post-coronavirus future? I think the lockdowns revealed that being cooped up in a small, noisy apartment is very different from being cooped up in a roomy house with a garden. Living in such an apartment is rarely a choice if you're low income. Some people manage nicely, but many don't, so one change I would very much welcome would be to make it possible for people of all incomes to seek out people of similar dispositions and have them create a living environment that suits them. Not necessarily bigger houses, but a grouping of people of similar dispositions: quiet people with quiet people, loud people with loud people, people who like to do DIY when everyone else is forced to be at home with similarly antisocial people.

For another thing, let's hope that, after being collectively and indiscriminately cooped up like this, there will be more attention paid to the variety of humanity: diversity in inclination, skin colour, gender, neurotype, sexual preferences, and so on. Humanity comes in so many forms, let's hope that the fact that the virus doesn't discriminate between people (unlike protective measures and access to testing) contributes to a world where these diverse forms can be celebrated instead of suppressed.

Tom

To give you more certainty, please note: local lockdowns and other restrictions will very likely continue well into 2021. "The new normal" gets mentioned, because it is possible that things will never quite return to the old normal. Many of us will find these changes stressful, Editor.

(Partly) in response to Lauren

It's one of the most insidious aspects of being autistic in an un-autistic world: people don't see you trying and assume you're lazy (keep in mind that uninformed assumptions say everything about the person making the assumptions and little, if anything about the person the assumptions are about). This is repeated so often and from such an early age that we internalise it and start seeing ourselves as lazy. We are not. You are not, Lauren. We do try, and sometimes, just sometimes, you meet someone who understands that. I think you've "met" quite a few of those people here, people who read *the Spectrum* with your article and thought, "Yep, I know how that feels."

Hi,

I have Asperger's syndrome. When I get home from work or another social setting, I feel mentally exhausted that I need a short nap to rejuvenate my system. I usually avoid socialising because I am not good at such. Is my mental exhaustion caused by information processing or is it also a result of sensory issues? Do other people with Asperger's syndrome experience the same? If I don't have a short nap when I get home after being in a social setting, I tend to get irritable. I fall asleep really quick when mentally exhausted and I feel energised again when I awake after an hour or so. I am a single parent and my child is designated a young carer to me because she is affected by my diagnosed Asperger's syndrome (and other conditions) — it's been tough but we have managed to cope and manage the best as we can since we have no other support from anyone else.

Sincerely,

Rachel

Dear Madam or Sir,

I'd like to submit a poem to the next *Spectrum* issue but am unclear of the rules. Can it be on any topic?

I've written about my devastating experience of being excluded from my church for two years due to my autism and comorbid anxiety and depression, although the poem is much subtler. It is however rather religious. Is that allowed? It is only five stanzas long. The epigraph can be omitted.

Thanks for your kind help and clarification.

Zimin

Any topic is allowed, although some readers object to religious pieces, especially things that can be construed as proselytising. As many people have turned to the church for solace during the pandemic, I feel that including this now is very appropriate, Editor.

The LORD is a God of judgment: blessed are all they that wait for him. (Isaiah, chapter 30, verse 18)

Sweet promise! All I now desire
For will, for cause, for light.
For evil hearts why fret and tire
When God dost fight my fight.

The Lord a God of judgement is:
All they that wait are blest,
E'en they that glean not what they sow;
His justice is my rest.

Vestured in still mightier seats,
These boast Thy pride and favour.
Yet Thou their flood, my quiet ark
Art, through my meek endeavour.

What greater sorrow than His Son
To crucify again
By men who once prostrate did vow to
By His sheep remain.

Fret not thyself, my sinful soul;
Thy Father dear dost weep
Where'er His child her brother rents
From His loving mercies deep.

Dogs' walks

by David

I am “walked”. I do not have autonomy. The halter is placed around my neck, and I am “walked”. I do not have a say in the matter. I have as much say in the matter as the halter, which, I understand, was placed around the necks of miscreants, those who transgressed, and who were then pulled up before finally falling down never to rise again.

And when it comes right down to it, should we also be used in figures of speech, metaphors, allusions, proverbial ___ bite, ___ bark, sleeping ___, “let slip the _____ . . .” All right. I'll let that go — it was, after all, the top dog of literature who coined it.

It started with the dawn of — what? Human understanding in . . . oh, can we put a number to it? When were we kidnapped from our wolfish beginnings and then forcibly adapted to be canine chums?

There has been, however, a new development of which you should all be aware. I refer, of course, to *The call of the wild*, which we now hear once more, as in the recent case of Chernobyl. The Worker Town has become a sarcophagus. We are now strays. You can adopt us, if you like. We were left behind when you left us, or, as you call it, abandoned the site for safety reasons. You can no longer spey, neuter or vaccinate us. We are rabid. We are also radioactive.

How canals helped me to recover from clinical depression and helped me to cope with a diagnosis of Asperger syndrome

by **Tim Price**

When my brother and I were young, my mum and dad used to arrange holidays with our friends from Sussex. During one of these holidays we decided to try a walk along the canal at Tyrley Locks, just south of Market Drayton, because this had been recommended to us (and was free!).

We went in our cars to Tyrley Locks and we were impressed with the canal although we knew very little about it.

We started to walk down from the top lock towards Market Drayton when a long narrowboat, which we subsequently discovered was the old, converted, working narrowboat boat, *Beatty*, was working down the locks (a famous boat in canal circles).

The people were very friendly and they offered us a lift on the boat: my brother went on *Beatty* but I did not want to go on it. The first experience of a boating trip was in 1979; it was very different from a working narrowboat: it had a rabbit in a hutch at the front.

The boat was travelling to the IWA (Inland Waterways Association) National Rally at Northwich. We went to the Festival on Saturday and we saw *Beatty* again. It was quite exciting because there was a bomb scare during the afternoon.

We were able to go on several boats, including hire boats. We were amazed at the spaciousness of them.

We really were keen to find out more about canals from there on and decided that we must hire a boat.

Our first cruise on a hire boat

The first narrowboat we went on was called the *Windsor Castle*. It was ten-berth, built by David Piper, although that did not mean anything to us then. We shared the boat for a holiday from the Peak Forest Cruisers base on the Macclesfield Canal.

There were two families, the Jarvis family and the Price family: we were children, aged between six and ten. The Prices had the front of the boat and the Jarvis family had the back; there was a galley (kitchen) in the middle. It was an ideal layout for two families with young children.

We all got on very well indeed, we had a great time on the canal system. The *Windsor Castle* was a 62-foot narrowboat which we booked again in 1982, the following year.

The bridge holes and especially the locks seemed very narrow but we learned to steer reasonably well — there was a good deal of “poling off” when we got stuck on the bottom.

We did the Four Counties Ring as recommended by Mr Palmer, the owner of Peak Forest Canal Cruisers.

The weather was glorious, hotter than our friends from Sussex expected, and we really enjoyed the holiday.

We went on three more canal holidays, two on the Macc and one on the Oxford (Mum and Dad also went with other friends on the Lancaster).

This was getting expensive so we decided to buy a boat.

I would really recommend a boating holiday to other people. The canals are very different from 1979 or even 1981 and 1982: there is less boating traffic and there are less working boats on the canal.

1984 *Picador*

Our first boat was a 24-foot canal cruiser called *Picador*, which was very small. It was all steel with an inboard, single cylinder, Petter Diesel engine, built by Black Bull Engineering, no shower, no stove, but it got us along the cut. It had wheel steering which took a bit of getting used to at first. It was moored on the Peak Forest Canal at Furness Vale.

Our first cruise along the Peak Forest, down the Macc, the Trent and Mersey and the Middlewich branch to Venetian Marine was interesting, we turned 360 degrees in the wind a couple of times.

We stayed at Venetian Marine for a while and then got a mooring nearer home at Middlewich.

We often went past the pub called the Big Lock and we went along the Middlewich branch and had days out with friends during the early years of owning a boat.

When we had *Picador* it was very different from the *Windsor Castle* which we hired for the first two canal holidays. It was much smaller and had fewer facilities but we loved it and enjoyed taking friends and family out for the day.

We explored the local canals and went to Chester and on the Caldon canal.

Slowcoach

After I left school I went to college in Crewe, but found it very difficult to adapt to a new routine. I became clinically depressed and had to spend time in hospital. Eventually the doctor found a suitable medication for me and I was able to come into the community and cope with life again.

In 1993, just after I came out of hospital, my mum and dad bought a forty-foot, David Piper, narrowboat called *Slowcoach*. They bought it so that the three of us could all go on holiday together in a good environment. I really like the wildlife on the canals and I have learnt how to do the locks.

We went to Worcester and I had a big steak-and-kidney pie in a pub, and I ate it all: people clapped when I finished it. I would not be able to eat it now because I am older and don't eat so much. I find it very nice to have meals on the boat but I also enjoy pub meals. We went on many cruises with our friends. They bought a boat called *Florence Rose*. I haven't been for a holiday on the boat for a few years but I'm hoping to go again soon. The last time I went was on the Ashby canal.

Some years ago we went along the Leeds and Liverpool Canal to Burscough. I had a pint of beer called Old Peculiar which was five per cent in alcohol, very strong for me. I liked it so much I went back for another pint. My dad called the beer "Wobbly Tim"!

Nowadays I write books which are published by chipmunka, the mental health and wellbeing publisher.

I have now had ten books published by

chipmunkapublishing.co.uk

They are:

How to improve mental health (this can be ordered from any bookshop, worldwide)

My Middlewich

My insight into the world of computers

The Olympic Games, London 2012

My memories of Manchester United

The World Cup, 2018

The changing world of mental health

Olympic Games, Rio 2016

My view of mental health services

Improving care in the community (this can be ordered from any bookshop, worldwide).

Daring greatly

by **Brené Brown**

published by Penguin Life

ISBN: 978 0 24125 740 1

£9.99

review by **Kayleigh**

Brené Brown challenges vulnerability and bravery. She proves how it is a strength to be vulnerable and how to incorporate a little more vulnerability into our daily lives. She uses twelve years of research across home, relationships, work and parenting. She drew the phrase “daring greatly” from Theodore Roosevelt’s speech in 1910, “If he fails, at least he fails while daring greatly”, which means to be bold, brave and subsequently vulnerable. She breaks down vulnerability from all stages of life and teaches what she calls “shame resilience”.

This book is incredible, I highly recommend. It is one of the best books I have read in the last decade. She explains how to be vulnerable we have to deal with our shame to develop “shame resilience” because we can’t be ashamed if we want to be vulnerable. She breaks down perfection and how it is an unattainable goal. Instead she

believes we need to cultivate shame resilience and be vulnerable instead.

Her research proves that vulnerability isn’t weakness and that it takes courage to be vulnerable. She defines it as uncertainty, risk and emotional exposure. Being vulnerable is sharing creativity, loving someone, trying something new. Being vulnerable means to dare greatly and let yourself be held up to a magnifying glass, allowing yourself to be put up for the judgment of others. I really liked the section about “sitting on the same side of the table”: she explains how feedback needs vulnerability and that both parties need to be vulnerable in order to have a successful outcome. She explains that only criticizing someone or leaning into anger because it is far easier than being vulnerable is unlikely to have a positive outcome, whereas if you “sat on the same side of the table” and took the time to both listen and communicate

the issue, but not forget that achievements are important too and it is helpful to express that appreciation or support. Otherwise the receiving party feels they cannot be vulnerable and ultimately feels inferior, as though their hard work isn’t appreciated.

My mentor recommended this book to me: she knows I am a very anxious person and I like to celebrate the small achievements and each time I handle something that makes me uncomfortable, it really is the perfect book for someone like me. It helped me to understand how vulnerable I can be on a daily basis and how others struggle to be. I have been trying to rebuild my self-esteem (which some days is easier than others) and I have found it challenging each time I have been told I did something wrong or I am not appreciated because someone thinks what they’ve done for me is more valuable I beat myself up about it and let myself shoulder blame and

a book review (continued) and an article

misdirected anger from others, causing more anxiety.

I know I have grown up trying to live up to everyone else's ridiculously high standards, but as an Autistic woman I know that I shouldn't be put up to the neurotypical standard. I took away from reading this book a new-found self-respect, I am not perfect, and I have tried all my life to be as good as everyone else, but in actual fact I am good

at things in my own way and I am successful because I manage the difficulties no one else can see while soldiering on every day. I hope one day people will learn to be vulnerable enough to treat me as equal while also respecting and listening to the things I find challenging.

If you are Autistic and you struggle to understand other people (or maybe you just find

them fascinating, like I do) give this a read: it's a really good insight into how other people might think without even knowing it!

I rate this book ten out of ten, absolutely fantastic: I am so grateful for my mentor recommending it to me! Each day try to be vulnerable, try something that scares you, tell someone you love them, express yourself! Dare greatly!

Change in the workplace

by Andrew

There is a misconception about autistic people that we don't like change. Whilst this may apply to some of us at different degrees, such as a spectral condition allows for, this does not apply to everyone. For me, change is something that is multi-faceted: what the change is, when the change happens and why the change has happened (and to whose benefit) are always something that pops to mind in the split-second that I detect a difference.

The "old" stereotype is that autistic people are very rigid, and why only 15% of us can get work. They cannot adapt to new norms, such as workplace or organisational restructuring. Unfortunately, according to my own personal experience, this stereotype still persists. Previously, I worked for a large employer who would make disruptive, last minute changes against my best interest whilst refusing to explain themselves or even believing that they were wrong, despite professional guidance that they were. These changes were things like meetings changing topics just as I entered them, so that I have no time to prepare; changes to attitude that contradicted basic decency; changes in stance (caring one minute to not caring the next); and

making arbitrary last-minute decisions with the sole purpose of getting irrational meltdowns. This can happen at any size company, so please speak up if this approach is taken at yours.

A workplace's attitude to change, especially with respect to their autistic communities, is absolutely essential for any company. Foremost, it is important to acknowledge that a change has taken place and, if it has caused upset, that the employer asks themselves what they have done to mitigate its impact. This lies with all parties, from managers to those affected by the change to those who wish to get to the root of a problem. If a change is needed, the culture and values of the organisation should first be considered. Change is a good thing, but only for the right reasons.

I think awareness of this fact is essential for employers to take on board, as it allows for a sense of ownership of change and for a culture that attracts and retains autistic people. This begins with intelligent, rational conversations and bringing all parties onto that level of discussion. That way, not only can the autistic community be accepting of change, they can also be that change.

How I learned to stop worrying and love lockdown

by Daniel

Like a lot of people on the autism spectrum, change for me can sometimes be an arduous process. During my time in the workforce and the type of young-adult upbringing I have had, I do think I can process and accept change more readily. I work in a section of the NHS that can at times, feel like a retail post. I administer key services, answer calls and take questions from medical staff that can sometimes change to the point it feels like liquid, rather than the safe, solid block of the request that was originally asked of me. Red becomes blue, up becomes down . . .

In other words, I'm used to change, to the point where sometimes the change can be a good thing, no matter how much of an upheaval it brings.

I take no pleasure in saying this. It feels like I'm being too positive in the context of a global tragedy, but for me, the sudden changes in my life that covid-19 wrought on us all could not have come at a better time.

I like my job. I used to love my job; but before the virus gripped the country, I was radically losing the joy in the occupation I once had. It's important to note why this was the case as I outline my case for being happy during the pandemic.

Firstly, there was a big change in staffing. I used to work as a team of two on the frontline of this service, but my colleague left for another post in the hospital. As a duo, we were able to manage the workload incredibly well. The trouble was the management did not get permission to replace them, and one doesn't fit into two as well as people might like to think it does. Suddenly I was running around haggard after every request, desperate to keep up the high standards we provided. It was a job primarily at a desk, but I was suffering physical burnout and my mental state was being battered as the work just did not stop piling in. Have you ever tried to catch a waterfall in a bucket? One thing that did offset this was that my managers were very supportive. They knew how tough it was out there and were always encouraging.

For various other reasons I was redeveloping symptoms of anxiety. I thought I had it crushed and conquered for so long, but like any insurgency it will rise again when given the push. I put a lot of pressure on myself to be the optimum, perfect person for everyone given the circumstances. I hadn't long started a distance-learning master's degree and because of the anxiety I was

feeling, I was developing a vicious cycle where I felt like I was underperforming for my family and my girlfriend, and although my family were understanding, my relationship with my significant other was breaking down fast.

I'm told when I'm anxious, my Asperger's symptoms show more, and I think that is correct. I don't have a lot of outward physical traits. I don't stim or melt down. I just panic and avoid anything that might stand a chance of having a negative effect, even when it could be extremely helpful. Most people I meet and socialise with don't even know about my condition, let alone claim that they "see" it in me. I'm essentially a chameleon. I don't want to be a chameleon, but I just don't trust the people around me would accept who I am and go right back to treating me as the person I was before the label.

I know I can really behave like a neurotypical adult with some slight social miscues. Therefore, when I do get nervous it's like there is another side to me.

Because of the external pressures going on, over time I certainly felt a greater anxiety about going out to places, spending time with

my partner, and whenever there was any dialogue that felt even remotely combative, my mind would regurgitate the negativity and crank it to eleven. This happened too often. The outward displays of my autistic traits caused the relationship to break down further, to the point where we agreed on a “break” in early March to try and work on our negative feelings and possibly reconnect after some time. Did I say I was doing a master’s degree on top of all of this? Fitting in essays around the destruction of my relationship and increasing work stress was not helping.

Then coronavirus was confirmed in the UK.

Almost overnight, everybody’s lives had turned upside down. On 23 March, my type of work was outlined by the Prime Minister as a place that had to shut down and if possible, work from home. Our work had been preparing for this, and we had a tangible, if imperfect, plan to carry on with what services we could provide. I went into the hospital on 24 March to close our physical space, and from 25 March I was turning on the PC in my living room to work.

Remember when I said that some change can be a good thing? I could work without having the constant distractions of staff to throw you off your current task. I didn’t have to deal with the crushing loneliness of eating

lunch on your own in a room full of people who only liked you when they needed you. I could work in my ideal environment. I sat on my chair, I listened to music on the job. I could slip outside to the supermarket nearby if the queues were short. It was work how I wanted it to be.

The social aspects of the virus were also oddly beneficial. The lockdown meant that it wasn’t possible to resolve my relationship struggles one way or the other, as we agreed to do that in person. The closing shops meant I had fewer distractions. Although I have a great relationship with my family, I talked to home more during the lockdown than before it. It was a negative that I couldn’t see my family, but I do understand that there is going to be a pot of gold at the end of the pandemic rainbow. At present, the thought that we will eventually be able to see them again is what has been keeping me going in this regard. This lockdown isn’t forever.

After I did one big shop to get some extra food in case I developed any symptoms, I stopped worrying about going to my local supermarket frequently. When I did, I was very happy waiting in socially-distanced lines knowing that when I got in, I could do a shop that wasn’t crowded, that had most people respecting personal spaces and conscious of hygiene. These things didn’t

affect me anyway, but it has been a nice touch. My social activities moved online and were largely unaffected. In other words, the almost serene nature of my home life was causing the big foggy bubble of anxiety in my head to slowly fade away, even if the changes came very abruptly.

Because this was happening, I came to some realisations. I realised that I was slowly killing my mental state with my high-pressure lifestyle, and sooner or later something was going to give. I was driving a car towards a cliff-edge at full speed, but the lockdown slammed the brakes, pulled up the handbrake and clipped me around the ear for being such a terrible driver. I identified some changes I could make and began to fix myself.

I am doing the bare minimum in credits per year to pass my university years. Grades-wise I am still shooting for the Moon, but I am taking workload and pressure off my back doing this. I have applied to a mental-health provider for help with my renewed anxiety and I am being treated for it. My girlfriend and I have just started online relationship counselling, and signs are initially positive. I’ve stopped thinking I have to be perfect for everyone. For my job there is no change, but I’ve been telling myself that I am not obliged to prove my worth to people. If they don’t want to be around me, I’m not forcing

an article (continued)

it just because I think that's right. I've given myself more of a voice to object if I feel that's necessary.

With a theme of uncertainty, change and how to cope, I can only offer advice on how I personally have been coping with change. I am not a scientist in any regard, and my advice won't be everyone's panacea. I remain hopeful, though, that somehow I can change someone with my tales and advice.

Use some time for introspection. As mentioned, I realised some flaws in my character and started planning to resolve them. I feel it's important to add that if there ever needed to be a reset button on life, this could be it. If you felt before that you were unable to enact change or felt nervous about the plan, why not resolve to work on it if you can't do it during lockdown? As soon as we're able to, we'll head back to work, plan holidays and look to the future as we always did. This is a chance to do it as a stronger individual with changes in mind.

As an extension of this, is there anything from the lockdown you would like to keep or try to retain going forward? I'm certainly going to be sad when my local supermarket goes back to the usual hustle and bustle, but I accept that is beyond my control. One thing I am going to try is to push for the chance

of working from home more often once we are back in the office. I've been told we will get our staff numbers back, so once that is in place, I'd like to push for more working from home. The more relaxed day will work wonders, even if it was on a once-a-fortnight basis.

On a smaller level, this is a good chance to find new things you like about yourself and the world around you. For example, I used to have a bit of an aversion to drinking tea. I could drink it, but I just didn't fancy hot drinks in general. Now I can't bear to imagine going back to work without having a morning brew! I have also taken to appreciating the space around me more. I live in a rented flat located in a parish just outside a big South-Eastern town and every other day I go for a walk admiring the scenery. I find it relaxing and the perfect complement to a quiet day of working at home. I've also taken to soft jazz music.

Finding a hobby or project would also be a good idea. I didn't do this one so much because I have been stuck working. I would have loved the chance to identify some big project or artwork to complete and work towards that. It would keep a loose routine and gives a focus instead of despairing.

It's hard to advise beyond this point. The

trickiest aspect of autism is that no two individuals are the same. There isn't a one-size-fits-all policy, something we will have heard all too often. I think it is a strong statement, but as the affected individuals, it may be best placed upon us to work out how best to adapt to the changes of lockdown. I don't mean this to be harsh at all, far from it. I just feel like if something is bothering us, we should say it, no matter how small it might be. Whether it can be made possible or not is usually going to be down to circumstances beyond our control, but as long as the interaction is civil, positive and at least sets the stage for future conversation, we'll feel better for saying it.

I'm going to be glad when the lockdown is lifted and I can see my family again, but I'll always remember the time I was confined to my flat, and how it saved me.



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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Asperger United delivery day

a reminiscence

by **Matthew**

Lands on my mat this magazine of challenge,
Spent of its bullet-force, Collector's now,
Analyst's, Champion's, Antihero's, Mine;
Sole, remaining, propulsive, potential effect.

This *Tablet* will help save my soul! This
Private Eye re-arm with cream-cake fun,
This *Punch* will civilise, or, civilize, this
Beano, begin again. Ript timely, this
Last king of Scotland eat me whole.

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