

Produced by and for Autistic people

The Spectrum

Edition **105** January 2021



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

NAS phone support: the Supporter Care Team

NAS database support: the Data Services Team

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

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

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

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

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

Please send all correspondence and subscription requests to:

Email: the.spectrum@nas.org.uk

The Goth
c/o The National Autistic Society
393 City Road
London
EC1V 1NG

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

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

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

Tel: **020 7923 5779** (geographical charges apply)

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

Contributions for the next issue should reach *the Spectrum* by **15 February 2021**

Welcome to the January edition of *the Spectrum*.

While I am writing this (in November) no sign of change in the pandemic is visible. Different parts of the country are going into and coming out of various lockdowns and semi-lockdowns, case numbers are up, down, and up again, and it looks completely unknowable when this situation will end.

For many people, Autistic and non-autistic alike, all this is very difficult to deal with, and I find myself repeating the adage from thirteenth-century (and possibly older) Sufi poetry, “This too shall pass.”

Inevitably, I then start singing *This too shall pass* by OK GO, and then watching the videos on YouTube — they did not one but *two* award-winning videos for the one song. Their video of them dancing on treadmills is pretty good too.

And so I find myself several hours later, having binged on videos. Another day it might be repeats of *Mythbusters* or *Time team*. I know this is because of the stress, and I want you to know that you are not alone or unusual in this. Times can be hard, but they will get better.

Yours,

the Editor

the new normal edition — suggestion for next issue on page 9

Contents

| | |
|---|--|
| <i>Isolation</i> cover painting by Ian | <i>Why being self-employed is a great career option</i> . . 12-13 article by Virginia |
| <i>Lockdown through autistic eyes</i> 4 feature by Samuel | <i>Aickman</i> 14-15 article-cum-book-review by Tony |
| <i>The new normal</i> 5 feature with accompanying letter by Nick | <i>The Autistic Adult Choir</i> 16 notice by Jill |
| <i>On the spectrum of acceptance and improvement</i> 6 by Joshua | Carved blocks 16 anonymous art |
| Pen pals 7-8 | <i>Notes from my diagnosis</i> and 16-17 <i>Notes from my life</i> paired poems by harri |
| <i>A kind of spark</i> 9 by Elle McNicoll book review by Kayleigh | <i>Perplexed</i> 18 poem with accompanying letter by Matthew Lacey |
| Letters to the Editor 10 one about Zoom fatigue from E Hill, one in response to Zimin from Sue, and one about work from Vickie | The rules of <i>the Spectrum</i> 19 |
| <i>Twenty years of solitude</i> – article by Tom 11-12 | <i>Outdoor living project</i> back cover notice by Ruth |

Lockdown through autistic eyes

by Samuel

When I heard that lockdown was first occurring in early 2020, in late March, I was partially mortified. I knew that I was going to end up being denied my freedom and suffer additional stress from the annoying activity from some of the residents I was living with.

One resident would every day play his music loud and start singing out of tune. The constant and endless noise was unbearable and ridiculous enough for me to frustrate over.

Lockdown is, in a sense, the equivalent of prison, only you're not sharing your cell with violent criminals that commonly threaten your body and existence with their harmful and violent capacities. I'd say it's like serving a sentence in a prison for falsely accused cellmates who are not truly dangerous enough to belong there.

It can be frustrating for me, sometimes, especially without coping techniques that I hadn't yet developed at the beginning of this lockdown era. It can be even more frustrating and unbearable for people with less capacity and understanding than I have.

Some people have kicked off because of this, I'd imagine.

On the other hand, the staff, the support workers and everyone else who supports people like us have made it well-understood that if they let us out, worse things would happen to us. Fatal severity, I mean. And by that, I'm referring directly to death. It was either death or a difficult journey back to normal.

Sometimes you do get very difficult and frustrating choices to make and often the best one still causes problems, whereas the other one leads to a worse path, one which even has the possibility of traumatising you.

I often look at myself with thoughts about making hard and emotionally painful choices. I tell myself, "You need to decide which choice feels like the worst one out of the two, and choose the other one, regardless of the consequences. Choose the lesser of the two severe examples."

In a case like this one, you need to suffer lesser negatives to stay alive. Do what you need to do to survive.

The covid-19 disaster has clearly killed more than a million people, and England was probably said to have suffered the worst level of it. That's what I perceived from what people were saying at the time.

During the opening stages of November in 2020, I was made aware that the disease was approaching Kent and that we'd be forced to reinstitute the inevitable possibility of lockdown. Another lockdown was ordered by Boris Johnson.

When the announcement was made on TV, I confess I wasn't that upset, as long as we had a deadline for its final stages. And once those final stages were reached and breached, the lockdown would be removed. The date for that was said to be the second of December.

There's always light at the end of the tunnel, as some people occasionally say. Light often represents hope, whereas darkness represents the opposite: despair and hopelessness.

Even though lockdown isn't yet over, I hope it ends soon. And, as I know, many people hope the same.

All we can do is wait, or even take advantage of waiting, by any means possible in our own individual cases.

Hello,

I share your feelings about Lauren's moving letter about the pain and confusion that Autism brings.

On the subject for October, I like many people have suffered from the lack of support during lockdown. I lived in a town where I had no family or friends so that made it even harder but, thankfully, there were some people willing to help with access to the Internet and advice. My biggest issue is the supermarkets and a lack of understanding. Yes, it has been a tough time for shop workers and I have witnessed verbal abuse being hurled at them. But I have been at the receiving end of verbal abuse back simply for asking for a little understanding and that having four staff shout over each other does not help me understand any better. Having to try and explain about eating a rigid diet was a strain and people simply cannot accept that I am unable to eat the suggested alternative product as I struggle with new and unfamiliar textures and tastes. Thankfully, the shelves are almost stocked up now so I am able to buy wholewheat pasta again.

I find having dyspraxia a big problem as staff do not understand how it affects my co-ordination and trying to use the escalator in store was a big worry as I felt like I was being launched from it and not simply stepping off so I asked to use the stairs as this was safer for me. Going up the stairs was not too bad but trying to walk down was scary as my balance is not good. I did ask to use the designated disabled door but this was worse than the work capability test with some staff even though I wear a sunflower lanyard. Not all the staff refused to let me pass and some were kind and full of understanding.

At the start of lockdown, we saw the real society as people came together to support and help others but sadly this goodwill has not lasted and now I see the return of the nasty and selfish people — maybe they have been isolating for the last three months? Now it is back to being shouted at for saying excuse me. Covid will go but how will it change us I wonder, for the better or worse?

Nick

The new normal

by **Nick**

The new normal is one of checking the ever-changing rules as to what you may or may not do today. Being able to stick to our routines has become even more difficult but it does prove even more comforting when we can slip in to our comfort zones and recover from the neurotype world. However, it does make the small things in life so much more rewarding and I now enjoy the delights of cycling in a group of six and not having to deal with so many riders around me when on the road. It does make the café stop so much easier, as I find the conversation simpler to understand and can add my own contribution. I have found a face mask I can wear and do not have to put up with being judged. The new normal can be hard when trying to explain to a young staff member that I am unable to use a phone and therefore cannot download the NHS app or provide a phone number, just an email. This normally results in strange looks and requests for a landline number. Thankfully I have an alert card and this does allow me to explain more about not having a phone and staff are then understanding.

Shopping has become easier now that the shelves are stocked and there is no panic buying. Now we are used to queuing and not having people stand too close which is a bonus for us on the spectrum. Some stores are now advertising the sunflower lanyard scheme and that not all customers can wear a mask so hopefully this will help to avoid unpleasant situations.

I hope that the new normal will allow us to develop a voice and not be pushed to one side and forgotten about as happened during lockdown. That there will be more support offered when and if local lockdowns are put in place.

On the spectrum of acceptance and improvement

by Joshua

Discovering as an adult that I am autistic has meant reframing the cornucopia of my life-long struggles. For example, I have shitty fine-motor skills; I suck at balancing; I sometimes look away in conversation; I bite my cheeks; I have sweaty extremities; I am pained by bright lighting; I repeat things spontaneously.

Or, I'm weird; I'm awkward; I'm different; I'm flawed; I'm gifted; I'm wrong; I'm special.

The best thing about this discovery? I've finally identified a single "cause" for every single one of the above labels and behaviors!

The worst thing about it? Asking myself: which of my labels or behaviors will I now accept to fit, and which will I reject to improve?

That's not to say that I can't accept who I am now, future improvements aside. I can and do (try to).

What I'm saying is that discovering I am autistic has meant realizing that there may be some behaviors or struggles that I need to reject in order to acknowledge that they can be improved.

Here's why I think this:

- (1) If I am autistic (because of my behaviors), then I will always be autistic — as most everyone agrees.
- (2) And if my behavior is what makes me autistic, then in theory I could only be able to improve (read: change) my behavior if I could become un-autistic.

But that's clearly impossible, as established above in point one, so I need to untangle this fallacy if I'm gonna make any sense out of it.

Take two of my behaviors, to illustrate: cheek-biting and balancing.

Since I was a kid, I have only received negative remarks around my cheek-biting: "What are you doing?"; "Stop doing that"; "That looks weird". Many of these came from my dad, teachers or professors.

Well. It's been twenty-plus years, and I haven't been able to stop, so where does that leave me?

This is precisely where the power of acceptance comes in.

Improvement failed in this case. I tried to quit biting my cheeks, and I couldn't.

So I've made peace with that and the adults who shamed me otherwise.

I have not — on the other hand — accepted that balancing is a lost cause for myself, instead continuing my martial arts practice of twelve-plus years in the face of all the progress I have made improving my balance thus far.

This leaves only one explanation as far as I'm concerned: my behavior will always be autistic, regardless of what it looks like (that is, improvements or none). In other words, autism is both a disability and a different ability, wherein some aspects can be impervious to change (say, sensitivity to bright lighting) while also being accommodated, such as by dimming or changing lightbulbs, and yet other aspects can be impervious to change for some but not others (say, difficulty balancing) while still being accommodated if necessary, such as, by providing hand rails).

So I will continue biting my cheeks in pride. And I will continue improving my balance in pride, respecting where it is in time.

Pen pals

Pen pal number 325

My name is Louis. I live in a small town in the county of Hertfordshire. I am 16 years old and am at college studying an employability course. I was diagnosed with high-functioning autism at the age of seven. My interests are politics (local and national), reading, writing fiction and non-fiction, cooking, history, and fighting for the rights of both children and young adults with autism and other learning difficulties.

I would love to meet someone that shares some of my interests. And to make a friend I am happy to email, or write letters; I am happy for anyone to get in contact with me, age is irrelevant. Thank you for reading. Take care, **Louis**

Pen pal number 326

Hi, I am Stefanie, 35-year-old woman. I was diagnosed just last year. I have other health conditions that limit my interaction with outside world. I also have learning difficulties.

My interests are a small black dog called Jet: he is a pug-cross-Jack-Russell. He's not mine but I love him so much. My other interests are politics, history, sci-fi. I also have a developing interest in photography which is quite new.

I would like someone who is also like-minded or to debate with, either is fine.

Many thanks

Stefanie

How to place a pen-pal advert

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

How to reply to pen pals

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

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

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

more pen-pal adverts

Pen pal number 327

Hi guys, my name is Sera, I am 22 years of age. I have an autistic-spectrum-disorder diagnosis and I was diagnosed at the age of 19. My disorder was first recognised at the age of 17 while I was doing my childcare NVQ and had had difficulties at school. My autism is mild-to-moderate but I am a high-functioning individual. As a child I struggled socially and with communication but now I love socialising although it can sometimes be difficult as I struggle with meeting new people. I'm friendly and outgoing and very kind. My hobbies include running and I've joined a running club. Walking has always been therapeutic to me when it comes to worries. I'm a keen watercolour painter and have sold some of my master pieces. I love music and because I listen to music frequently, I'm really good at recognising different tracks and artists. I work with children on the autistic spectrum and I absolutely love it. I've been working with children from the age of 17. What I love about it is that I see their struggles and I'm able to help as I understand what they go through. I'm looking to hear from someone who is like me and can share interests and certain things we find difficult. I would also like to have tips on how people have dealt with situations like interviews as this is an area I find particularly difficult. Please get in contact. Looking forward to hearing from you,

Sera

Pen pal number 328

Hi, I'm Emma and I'm looking for a real friend. Someone caring, kind, loyal and who will never leave me behind. Someone who I can share laughs, tears and inside jokes with. I know that I am all that. If you want to know what I like just ask me. I won't bite. ;)

Greetings,

Ems

Thirty-one pen-pal adverts have been held over for publication in the next six issues, Editor.

Pen pal number 329

Hi, I am 43 and live in Scotland. I have autism, adhd and dyslexia. I love going to the gym, walking, running and cycling. I like watching movies and wildlife and learning about animal and human behaviour. I believe no obstacle can stop you from pursuing your dreams and goals no matter what the circumstances.

Cubra

Pen pal number 330

Hi, my name is Hannah and I'm 35. I was only diagnosed this year so all of this is rather new for me at the moment! I love receiving real letters so I'm excited that this is a section of the website. My special interest is dinosaurs, but I'm interested in all sorts of history in general. I watch a fair bit of TV and my favourite shows are *West wing* and *Stargate SG-1*. I very much enjoy reading, and I write fanfic. I have two original novels written as well, though they're not edited because *ugh*. I really enjoy cross-stitch and colouring too. Looking to "meet" like-minded people who I can talk about all sorts of things to. I'm liberal political and happy to talk about current affairs too. Have a nice day!

Pen pal number 331

Hi. My name is Ben.

I am 28 years old. I like traveling to different places. I enjoy doing martial arts and learning different languages. I like video games and pro wrestling. I like listening to music also.

I would like a pen pal.

A kind of spark

by **Elle McNicoll**

published by Knights Of

ISBN: 978 1 91331 105 6

£6.99

review by **Kayleigh**

I loved this book. Yes, it is aimed at children, but it is the first time I have read a good, genuine representation of Autism! This isn't even disclosed until you start reading the book, nothing on the blurb or cover, so I am sure many people will pick this up having no idea and finally learn something about it. Elle McNicoll is Autistic herself and says she wrote this during an incredibly angry time in her life; she is brutally honest and that is why I love her so much. (Some of the best work comes from the strongest emotions, anger, sadness, love, joy!)

I fell in love with Addie in the first chapter, my heart broke for her knowing the pain being bullied can cause. I was rooting for her and her new friend Audrey to raise

awareness and money for the memorial.

The bond Addie had with her sister Keedie was beautiful and their ability to speak to each other in a way that no one else could understand. Keedie guides Addie through her struggles with Autism as Keedie has already gone through it. Keedie's twin Nina isn't like them, she doesn't really understand them and honestly I didn't like her all that much at the start but when an incident at Addie's school means both sisters are called in (as Addie's parents were both working) I began to see her in a different light.

It was an amazingly easy read (regardless that it is a children's book) and quite emotional for me as I have

never felt so well-represented. I read it in about an hour spread over a few days! I also think it is a really good length for this type of book somewhere around 200 pages with a comfortably sized font.

This gets all of the stars, if you ask me, unique, exciting, and many doors opened for disability representation in books (that isn't just for comedy or to humanise someone else)! I want more books like this, and I really hope that Autistic kids can pick this up and finally see the representation that they deserve! I think the author and Addie are incredibly inspiring, so I know I will read this time and time again.

That's what my Autism is. It's like a kind of spark.

If sufficient material is sent in, the theme for April will be **coping day to day in 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

Hi, Editor,

have your readers heard of “Zoom fatigue” and thought, like me, “Join the club!”? Neurotypicals seem to experience conference calls just like me, an autistic person, when I experience ordinary, everyday social interactions — that is, eyes staring out at me, no eye contact, no recognizable faces, random bits of bodies coming in and out of focus, no cues from subtle body language — and therefore no rhythm to the conversation. Autistic people feel as if they are helplessly participating in a Zoom twenty-plus-person conference call all the time — well, I do anyway. Do other people agree?

Stay safe,

E Hill

Dear Editor,

in response to Zimin’s letter of the October issue: as you know I too was expelled, excluded from church. For many years my anxiety was permanently sky high.

We need to get something done about people who are autistic being excluded from church. The place where we are supposed to be loved, cared for, forgiven. Not condemned for being us, for being what we see as normal.

It would be interesting to get an overview of which denominations are the worst offenders of this.

The church wouldn’t exclude someone in a wheelchair or who brought a guide dog. We too come under the disability act.

The church must make reasonable adjustment. Mine has had to — everyone else must do too.

From

Sue

Dear Editor,

I was diagnosed at 44. Before I knew I was autistic I struggled with anxiety, panic attacks and depression, both at work and in everyday life. I found working as a housekeeper on the inpatient ward at a hospice challenging and I used to have panic attacks and daily anxiety, especially when I was around other people. Since being diagnosed I understand myself better and now realise that my panic attacks were actually due to sensory overload, which led to meltdowns. All of my senses were in overdrive from the amount of people, movement, noise, bright lights and smells. Patterned clothes such as zig zags, stripes or spots made me feel sick. With support of my line manager and Access To Work I was able to get a pair of coloured glasses. These are for visual stress and help with bright lights, escalators, lifts, travel sickness and patterns on floors or clothing. They have made a huge difference to me as the floor used to move when I looked down. Now it doesn’t, which is a big relief as it makes doing my job and everyday life a lot easier.

I take things literally. If you say it’s raining cats and dogs I actually see cats and dogs falling from the sky in my mind. I see most things people say in pictures. After all the noise, lights, smells and social interaction of the day at work I have to go to sleep for an hour when I get home to bring down my senses and calm my brain. The hospice has supported me with this by allowing me to work a shorter day and start and finish when the trains aren’t too busy. The hospice also moved me from the inpatient ward to a quieter part of the hospice which isn’t as overwhelming. I can have a sensory break whenever I need one and the spiritual care lead at the hospice has been particularly supportive.

I’m extremely grateful to the hospice for all the support and adjustments they have made to enable me to continue to work. Only 16% of Autistic people are in employment; being able to work means a lot to me and I see this as a huge achievement.

Vickie

Twenty years of solitude

by Tom

When I was about eleven I regularly played outside with our neighbour's kids, two and three years my junior. I'd caught up with my younger neighbours' psychological development level only then: I'd finally figured out what they were up to well enough for me to join in. I've always been socially awkward, but tried my best to understand the rules and apply them: trying to do consciously what comes instinctively to other people. Because I was figuring out things after the fact, life always seemed to move too fast, just out of reach for me. Throughout school and university, lasting friendships and social interactions were especially hard to come by. Until, that is, some five years into my university studies (it would take three more years to finish, longer than officially sanctioned but not unusual) when I finally found a nice student accommodation. Usually, finding a place to live entailed presenting yourself to existing residents along with dozens of other hopefuls. Of course, I never got picked so I put my name down for an accommodation that was assigned through a simple waiting list. It was quite luxurious by student standards: you had a bathroom and kitchenette all to yourself, only needing to step out to do laundry (and most people still had their mums do that). Perhaps as a reaction to that, the floor I ended up on was extremely social: doors were open all the time and people gathered regularly. I tried to join in, buoyed by the fact that I'd also landed a girlfriend. I never felt more normal. Surely life wouldn't run away again?

No. No more. Please — I just cannot be around people anymore.

But of course it did. Try as I might, I could not shake the awkwardness and feelings of being completely overwhelmed. I've always had depressive episodes, but they became worse. Worst of all, I had no idea why this was happening, apart from the obvious fact that I was, somehow, defective. Looking back, it's obvious I was so

obsessed with fitting in that I had no opportunity to make contact with my emotions, which meant I couldn't really feel connected to others (because you do so at an emotional level) or feel safe with groups of people. So when people started moving away from the student home, the new occupants kept their doors shut and the social life on my floor died down: I was fine with that. My relationship had ended, so I wasn't feeling particularly social anyway. I concentrated on finishing my studies. When I did, I moved away as well, to a "normal" rented apartment in a notoriously bad neighbourhood. No wonder I didn't make any contact there, then, was it? I occasionally tried to do something social, but increasingly half-heartedly. Gradually, subconsciously, I gave up. More and more I isolated myself, shunning social settings altogether. Not because social settings weren't appealing, but because I felt I had to protect myself from the awful sensations of being completely overtaxed. Probably also because I didn't want to be confronted with my otherness (or as I'd have seen it then: deficiency) and solitude. It never felt entirely right, like I was denying myself large parts of life. However, it seemed apparent to me that I could not do "social".

Some ten years later I found myself with no social life and a dead-end job with no prospects. Something had gone wrong and an answer was needed, which turned out to be Asperger's syndrome. So I launched myself into therapies to try and make my life better. And it did: I got another job (well, series of jobs) with a temp agency that specialises in autism, which is a veritable heaven compared to my old job. I even met someone on one of my assignments who became a very good friend, soulmate even (her words) and my mental health improved as well. But still I shunned a lot of activities, especially anything involving groups. I limited my social interactions to one or two people at a time — the only setting in which I occasionally didn't feel

an article (continued) and another article

awkward, and even then it was mostly at work. At heart, I was still convinced that I had to limit my social interactions.

This has gone on until recently, another ten years later, an odd thing happened: I found myself at a series of social gatherings. What's more, they had nothing to do with work. The first two meetings went as I'd expect — awkward, overwhelming, unable to make contact (with myself, and by extension, with others). This confirmed my suspicions that I couldn't "do" social, or at least groups. But the third meeting was different: awkward, yes, overwhelming, yes, but I found myself being able to make contact for the first time, even to feel some sense of safety. That, somehow, unleashed a hurricane in my head — surely there was the proof that those twenty years of solitude had been for nothing! Here I was, in a group, feeling safe! If only I'd tried a little harder back then, that would have been there all along and I wouldn't have wasted twenty years. Surely after all these years, it was too late to change.

But that's not what happened. It is precisely because I have spent ten years getting to know myself, learning to be milder towards myself, learning to experience the grey instead of seeing only black and white, that I was able to experience this. This wasn't some cruel cosmic joke I'd essentially played on myself: this was, this is, progress. However, it is also tragic that I felt I had to deny myself so much of life for so long — it's no wonder that's causing me grief. I'll have to come to terms with the fact that my vulnerabilities are here to stay and I'll have to deal with them on their own terms. I suppose by isolating myself, I tried to cut out so much of life that I wouldn't have to face these vulnerabilities. That's not how it works, though, and going by my recent experience, that's not how I want it to be either. I'll have to (and will) find help to deal with these vulnerabilities rather than run from them. I thought I'd gotten most psychological breakthroughs out of the way by now but maybe, at 45, I've opened up a whole new chapter.

Why being self-employed is a great career option for autistic people

by **Virginia** (weathering the storm of the pandemic at home)

In 2013, after sixteen years of secondary-school teaching, twelve of them in a nice, well-behaved private school, I left to set up my own tuition business. In my case, it was a fairly spontaneous decision, precipitated by a lot of unrest in my personal life which contributed to a spot of bother at work. It looked like I would have to jump ship before I was pushed, so I took the plunge there and then. Whilst I was still working for my employer, I took on three tutees after school, and, three months later, I left work and grew very quickly to a fully-fledged business with twenty-six clients. The risk had paid off, and I have never regretted this decision.

The problems I had encountered at work were not my fault, and nothing to do with the

quality of my work. But my personal stress co-incided with a change of management, and for many neurodivergent people, any change has the potential to be seismic. Because of our communication styles, the way we are perceived to react to situations can often be misinterpreted, and we are vulnerable to bullying. Looking back at my entire working career, not just in teaching, but in every job I had worked in, any problems I encountered in the workplace were directly related to colleagues or line managers, who just didn't understand me. There were occasions when I found a gem — the mad woman at the freight-forwarding company who calmly understood when I sent a parcel to Australia instead of Amsterdam, or the Sherlock-Holmes-style Head of English, with the massive intellect and wicked sense of

humour, who thought parents' evenings were just not for him to bother with. Apart from these memorable kindred spirits, I often considered the people in charge of me to be frustratingly "jobsworth" and many seemed to be, well, a bit stupid. Hours of pointless meetings and red tape; report writing six times a year to say the same thing six times; worst of all, "workspeak" — the jargon peculiar to the particular industry you are in. In teaching, I began my career with the buzzword "differentiation" looming large over every needless lesson plan, and ended it in an institution obsessed by "growth mindset" — which for various reasons I considered to be laughably ironic.

Since I became self-employed, I have extolled its virtues to anyone who is curious. Apart from the lack of annoying colleagues, full control of your product, and dispensing with pointless meetings and paperwork, you have free range to take on as much or as little work as you want, work from home, and tailor your hours to suit yourself. There are tax advantages too. I don't cheat the tax man, but I do pay reasonable tax bills compared to my husband's extortionate ones. It is important to have a good accountant as he or she will help you claim all the expenses you may not have considered you were entitled to.

Until last month, I felt that being self-employed was the future way forward for the world. However, during the current coronavirus crisis, I have been forced to re-evaluate, and what I have found is that I am incredibly fortunate to still be working in a job I love.

There has always been a downside to self-employment: no sick pay, no holiday pay — if you don't work you are not paid. In tutoring, this means I have to mark exams in the summer as I don't work as much during those months. I also have to advertise (although I don't spend much and, luckily, I was known enough to gain clients by word of mouth, which still continues). For those of us who enjoy socialising, being at home can be quite isolated, although not all self-employed jobs are like this. Recently though, covid-19 has impacted everyone, but the self-employed have

been hard hit. The government have begun to offer help to those they consider eligible, but we have also had to do what we have always done to an even greater extent: save money as a fall-back and be versatile. Some fellow tutors and other workers such as hairdressers have lost all their clients. I have not suffered too badly — I have lost six clients but gained six new ones from my waiting list. I lost the summer money when the exams were cancelled, but I have saved back enough to cover this. I was adaptable enough to move my business on line, and was able to "sell" this to loyal customers — you quickly learn how to improve in your dealings with people. I was always versatile — I spread my skills from secondary, teaching GCSE and A level, to the full range from age 8 to adult, so when the exam students left, I had others who remained. I am lucky enough to have two incomes in the household too.

But for all that, working for yourself is still a brilliant career option for autistic people. According to statistics, many autistic people are unemployed, and this is often due to bullying at work or lack of support. So many of us have specialised talents, and can offer a great service to others or contribute our skills in ways other than in the traditional workplace. Many autistic people feel validated through their work, and even find work a way of de-stressing — in the right environment. And if you have other hidden disabilities, what better way to work than to fit it around your own time and in your own home.

The best thing I have found is that my hobby of analysing and reading earns me a living. I help others with my skills, and I even have time to pursue other interests like music and writing — I became a published author last year. If I am having a day with few "spoons" available, I can re-schedule my work around this, although whilst I am working on line, I only have to go downstairs to be in the office, so I can also get away with working in my PJs! I would urge anyone who finds it a struggle to go to work, or maintain a job in the traditional sense, to take stock of their skills and interests to see if they could utilise them by turning them into a new career. After all, it might just pay off!

Aickman

(connects to canals reply from last issue)

review by Tony

Robert Fordyce Aickman wrote forty-eight stories which were originally compiled into eight volumes. This entry is a review of one of these volumes (*Dark entries*, 1964, Tartarus Press). Aickman edited the first eight volumes of the *Fontana book of great ghost stories* and, with Elizabeth Jane Howard, cowrote *We are for the dark*, a collection of ghost stories. His father was an architect and his grandfather, Richard Marsh, wrote *The beetle*, a horror story that at the time was almost as famous as Bram Stoker's *Dracula*. He seems to have had a strange childhood and found his father perplexing, according to his autobiography (*The attempted rescue*). This may explain his style of writing and his dislike of childhood and children because although he married, and had an affair with his co-writer, he never had any offspring. He was a member of the Ghost Club, and the Society For Psychological Research, investigating the famous Borley Rectory haunting in Essex. He was also a theatre critic and co-founded the Inland Waterways Association, which rejuvenated the British canals system. He died in 1981 at the age of 66 after refusing conventional treatment for cancer, in favour of homeopathy. For anybody

new to Robert Aickman's short stories, this collection may appeal and gives a good idea of his style. His stories leave both the main protagonist and reader perplexed as to where the story has gone and what really happened. MR James, the British writer of ghost stories, by contrast makes everything clear by the end, even if the main character is perplexed by events or even killed by them. As for HP Lovecraft, the American writer, he spells it all out for you after saying that it is all too indescribable to put into words.

The school friend

The story that kick-starts the volume is about a friendship that develops between an ordinary, middle class, girl and what we call a swot in the UK. The father of the latter girl seems to be a foreign academic, who inspires his daughter in her scholarly pursuits, which is not unusual in public schools. The mysterious father dies. The daughter, now an adult, returns to the family home after a distinguished academic career and the friendship is renewed. So far nothing that unusual, then the girl is knocked down by a vehicle and

is expected to die. The matron of the hospital asks her to pick up clothes for her friend's hospital stay.

When she enters the building, she finds all the rooms are locked and when opened up, sparsely furnished. Eventually she ventures into the library, used as a bedroom by the father. It has bars on the window and when she draws the curtains, she catches the fleeting sight of a figure — gaunt and deathly (a recurring motif of the writer). A final revelation leaves the whole situation open-ended, which would have pleased John Carpenter, the director, as this is a style he was famous for in his films.

Ringling the changes

This is Aickman's most famous story, having been made into a BBC television film in 1968 and more recently a radio play, adapted by Jeremy Dyson (2000). It's about a honeymooning couple arriving at an East Anglian seaside town in the middle of nowhere. On arrival they hear the church bells ringing and assume it is some kind of practice session, but as they

a book review (continued)

are to discover, it has a much more sinister purpose than that. The hotel where they are staying is run-down and seedy, the landlord nowhere to be seen and the wife seemingly the worse for alcohol consumption. The only other guest, a permanent resident, warns them to get away as quickly as possible. Then the bells stop and all hell is let loose.

Choice of weapons

Aickman's stories speak of a world gone by, slightly seedy and decrepit and *Choice of weapons* is no exception to this run-down feeling of post-war Britain. A mysterious woman at a restaurant, a frantic pursuit and a malevolent stranger, followed by a sword fight, a theft and a vampire's kiss. All this, set against a backdrop of Egyptian architecture and failed romance, rounds off the story.

The view

In this story the main protagonist, a government official in the Foreign Office, takes a trip on a boat out of Liverpool. Travelling to some undisclosed island, he meets and falls in love with another passenger, who invites him to her house. During the day he paints and she goes off riding. Strange carpeting, the appearance of a monstrous figure, and the ever-changing view from his bedroom

window perplexes him as the civilized world creeps in daily upon his idealized landscape of cliff and sea. Eventually that is all he sees as the town draws him back to reality and his lover vanishes. In the mirror is reflected an old and dispirited man, like a visitor to fairyland, who thought he was absent for a short time but really it was years.

Bind your hair

This is one of his stories that baffles by its unrevealed actions and half-exposed players. Once again, as in two of his other stories in this collection, there is a male character that looms menacingly, almost inhumanly. A woman visits the home of an office colleague, to whom she is engaged, meeting some locals in a get-together — including an eccentric woman who lives in a graveyard. The following day she goes for a walk in the woods, running into a herd of pigs and two strange children, plus a silent and menacing herdsman, near a maze. That night she returns, witnessing a strange and baffling procession of either naked people or fur-covered ones. If it were a stone circle, instead of a maze, you would think it was some pagan ritual but in this instance, you are not sure.

The waiting room

This is the shortest of the stories. It is about a

traveller who misses his train connection and is forced to spend the evening sleeping in the closed station's waiting room. He seems to wake in the night to find the long-disused stove alight and himself surrounded by fellow passengers. He is then woken up for real, this time by the day porter, who tells him the other porter shouldn't have let him stay there. This, he says, is because the waiting room is built over an old prison graveyard and has an unfortunate reputation. He also tells him that he should see his doctor when he gets home as he has acquired the same nervous tick that the night porter has.

Don't be a stranger

Aickman always referred to his writings, not as ghost or horror tales, but strange stories, and this collection displays this quality in a fresh, sharp manner. Other books in this series are published by Faber and Faber and include *The wine-dark sea*, *The unsettled dust* and *Cold hand in mine*. His original publisher for these items was Tartarus Press.

Anybody interested in finding out more about Aickman may find information at the British Library, which has a section dedicated to his manuscripts and other papers. Bowling Green State University in Ohio, USA, also has a collection of his papers.

The Autistic Adult Choir

notice by **Jill**, the Choirmaster

The Autistic Adult Choir is looking for singers. If you are an Autistic adult or young person, you are welcome to join one of our Zoom sessions and find out if the choir is for you.

If you enjoy singing, or think that you might enjoy singing, please consider joining us. You will be singing in a non-judgmental, supportive environment.

Zoom sessions are currently being held due to covid-19. We meet Tuesdays and Thursdays between 7pm-8pm.

If interested, please email or call:

Email: contact@theautisticadultchoir.com

Choir's mobile: **07495 725 984**

Please see our website for more information:

<https://www.theautisticadultchoir.com>



by **anon**

Notes from my diagnosis

I am deficits,
disorders,
and abnormalities.

Difficulties,
restrictions,
and limitations.

Inabilities,
sensitivities,
vulnerable.

I am kind and considerate,
but cold.
Accomplished in everything I attempt,
but intolerant of imperfection.
I am fearless and confident,
but anxious.

My responses are disproportionate,
(I am always too little
or too much.)
My speech is clear and easy to understand,
but too quiet.
I'll smile when you make a joke,
(if I realise it's a joke at all)
but not just because you smile at me.

I have no interest in casual friendships,
but am easily led and manipulated.
I'm clever,
but have no common sense.
I eschew conventional gestures,
I am atypical,
unusual.

I'm blunt,
(I tell the truth,
funny how that's seen as a problem.)
Conversation does not come naturally,
I'll panic if you don't follow my script.
I cannot empathise spontaneously,
(what does that even mean?)
But I will try and fix things,
And if you ask, give you a hug.

paired poems (continued)

I am reduced to a list,
A diagnosis,
a disability.

The myriad parts of me
dissected,
and judged.

The labels are all people see.
The acronyms
stamped on my soul.

Incapable of love.
Or of empathy.

A robot.

Conversation is hard,
small talk is painful.
But tell me your passions.
I'll listen.

I am my own calm
in the storm of the world.
Where everything hits me at once.

I can retreat into silence,
and a perfect focus,
I strive for perfection
because I know that I'm capable.

I can manage anxiety,
and sensory overload,
triggered at the drop of a hat.

I throw myself into interests
with childlike enthusiasm,
because life is a game, after all.

I see beauty in details,
in patterns and colour,
in the order of numbers and science.

In the sound of a word,
as it repeats on my tongue,
making peace in the middle of chaos.

I am more than a list,
I'm a constellation of stars.
My darkness is spangled with light.

I can't write a poem
about all that I am,
I can't be constrained
into lines.

If I'm a robot,
I'm Data with his emotions chip on.
Everything intense and overwhelming.
But there's persistence in confusion,
strength in despair.
And I'm only cold if you don't care enough
to really look at what's there.

Notes from my life

I am intensity,
curiosity,
and creativity.

Ambition,
acceptance,
and logic.

Talented,
resilient,

strong.

I will drive across the country,
if someone I love says they need me.

My friendships are few,
but precious.

I'll trust what you tell me,
until you're caught in a lie,
better that,
than to live in suspicion.

a poem with accompanying letter

To *the Spectrum*,

my name is Matty Lacey and I'm an Autistic spoken-word artist, performer and philosophy student at Newcastle University, living and proudly coming from, the North East.

I'm a huge fan of *the Spectrum*, and all of the amazing pieces that feature in every edition, and it would be an absolute honour, and subjective privilege, to be published in an edition.

I am happy to be credited and named as Matthew Lacey, and it would be hugely appreciated if you could include the link to my spoken-word blog page at

<https://truthstunestoon.wordpress.com/blog/>

Matthew Lacey

Best regards, and love and strength going forward at this surreal yet enlightening time!

Perplexed

Now political factions seem perplexed when you get your thoughts off your chest, when an individual opens up about personal issues and stress.

They say there is no contest, and that comrades should never rest, yet when you speak from the heart people want to put you under a test, a test of the mind, a test of the supposed divine, all I wanted to do was speak up for the boys that can't rhyme, now is the time, to stop all the bitching and lies, open your mind to a world where people are not just victims for likes.

Prophecise that this is all of your times if no one speaks up for hearts and minds, we might as well all wear a disguise, cover up what's behind the eyes, all the performance of suffering and struggle leaves people blind to the times, the hard questions and reflection, kids growing up cannot fathom a pension, so used to being in detention, for not following the sentence, the sentence of some educators just a twisted form of oppression.

This is not just a lesson, a freedom of expression from the mind coming up who has been preached at, grieved at, because of depression, this is why I have started this session, as I fight for my independence and that of the lives of the people who need divine intervention, now here is the question, are you a man, beast or a weapon?

Are you all in one and more when you question a classist, racist nation that uses repentance to control and manipulate your sentence?

Now is the time for emancipation, to break away from the chains you were born in and raised with, faith is needed, but even more so is a break away from inflation, be fragrant and blatant, no surrender to an individual ego that exists just for a Facebook generation.



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 NAS website. 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.

Outdoor living project

New Year into Spring

notice by **Ruth**

Memory Gardens invites:

children and young adults on the Autistic spectrum

to book a Sculpture, Art and Sensory Session

in London, Hackney, at: Robin Hood Gardens, Spring Lane, E5.

Sessions will run every Friday between 10 am and 3.30 pm.

You will need to book a one-hour session in advance so that we can maintain small covid-safe groups.

We'll make balance sculptures, use leaves, decorate and enter shelters, make fires, listen to

the sounds around us in this special place beside the River Lea — a hidden gem in London, Hackney.

You will be joined and supported by an Artist/Tutor. Parents and allies are encouraged to attend and join in too.

Cost: £3

Let's make something together!

Call Ruth on: **07940 890 418**

Email: yellruthtoday@yahoo.co.uk

Website:

www.handandskyproject.yolasite.com

The Spectrum, c/o NAS, 393 City Road, London EC1V 1NG
Telephone: **0808 800 1050** (free from most landlines) or
Telephone: **020 7923 5779** (geographical charges apply)
Email: the.spectrum@nas.org.uk
Website: www.autism.org.uk/thespectrum



Except where stated, all material © National Autistic Society 2021