

Produced by and for Autistic people

The Spectrum

Edition **114** April 2023



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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 is owned and run by the National Autistic Society, and 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

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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.

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

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

Please send all correspondence and subscription requests to:

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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 **12 June 2023**

Welcome to the very delayed April edition of *the Spectrum*.

I am sorry for the delay; the severity of the problem snuck up on me, so I was totally unprepared to almost completely lose IT contact with Head Office.

These computer problems began on the first of December and got worse in January. So much worse that it was almost impossible to work, and any solution had to be carefully checked by IT experts so that the National Autistic Society could be confident that we were meeting our obligations under various laws. And it turns out that that is even more complicated than it sounds.

Anyway, about four weeks late, here we are. I am sorry for the stress and anxiety that this unexpected delay will have caused for a number of you, and I hope that the robust solution (a machine that, while not new, will be new to me) will be installed smoothly and in time for the work to start on the July edition. I will have to start that work a little later than usual, at the beginning of June.

I shall be looking forward to the postbag, as ever.

Yours,

the Editor

the masking edition – suggestion for next issue, page 10

Contents

Painting of a fox. cover by Stephen Plant	<i>Assessment (what I wish I'd said)</i> 11 prose poem with illustration by Bea
<i>Masking</i> 4-5 feature by Blossom	<i>Bonding over Vera</i> 12-13 story by S Bee
<i>Masking</i> 5 second feature by Katie	<i>Ceilings and staircases</i> – poem by Tom. 13
<i>Autism musician</i> 6-7 article by Ellie Patricia	<i>Unmasking your Autism and 14-15</i> <i>healing your trauma</i> article by Noah
<i>Unmasking my creativity</i> 7 article by Sam Barnes	<i>Autism and Buddhist practice</i> 16-17 edited by Chris Jarrell book review by Emily
<i>Masking</i> 8 poem by Katie	<i>What I want you to know about</i> 17-18 <i>autistic women and girls</i> article by Tracy Smith
<i>How Dungeons and Dragons has been 9</i> <i>beneficial to me</i> article by Lucas Maxwell	The rules of <i>the Spectrum</i> 19
Letter to the Editor. 10 about being tactless from Paigetheoracle	<i>The joys of bread-making</i> back cover article by Nick

Masking

by Blossom

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When I think about autistic masking, I imagine myself wearing one of those plastic glasses-nose-moustache combos that you see detectives wear in slap-stick comedies. They think they're well disguised but their mistake is plain to see to everyone around them. It makes me laugh and reminds me that the real me is a better option.

Apologies I've started in the middle. Let me introduce myself. Blossom: late diagnosed autistic mum to three autistic children. Anyone in my situation with multiple autistic children with even a modicum of self-reflective ability would have peered into the mirror and wondered if they were the tributary to these wonderful neurodivergent humans. Over those years of getting the children diagnosed, I wondered to myself. There was clearly a link somewhere, and I was certain that it was pointing at me.

And hadn't I always considered myself a bit quirky? My slightly antisocial saltiness made up part of who I was. My friends *liked* that about me! Never one to really become embroiled in drama — I mean, how could I? — I have little experience of large friendship groups which require a lot

of maintenance (I am lucky enough to be included in a group of warm and accepting long-distance friends whose demands and expectations are minimal), preferring singular friends picked up along the way on my various paths in life. A motley crew of individuals with no connection whatsoever, other than me. No tricky dynamics to navigate. All hand-picked people I didn't feel the overwhelming need to filter myself for. That filtering as I called it, turned out to be masking.

But even having had my suspicions for so long, I still struggled with the idea of pursuing a diagnosis. "I have managed all these years" I would think to myself. "What's the point? No one even suspects me." (That turned out to be wrong.) "I will just quietly self-identify. Where's the harm in that?" I felt like I was always operating undercover — I was watching the world's comings and goings through a newspaper with a hole cut out (wearing my plastic glasses-nose-moustache).

But . . . there was always a but; a question mark. Why was I finding it all so difficult? Why was my constant need to filter my personality so exhausting? Surely everyone

had to dilute and sterilise their personality before unleashing it on unsuspecting victims? But if they did, why didn't everyone else seem to be more exhausted from it all?

No. The rule abiding part of me felt very strongly that I needed to have it rubber-stamped by a professional. I needed answers. And how could I raise my children to be proud of their autistic identity if I couldn't face my own?

"I'm very privileged to be able to pass as a neurotypical person," is something I've told myself many, many times. But then I realised something. Whilst there are some advantages of course, it's not necessarily as "lucky" as one may think. Masking as a neurotypical person is not a "get-out-of-jail-free" card. It's not a pass for an easy, carefree life. Masking is not fun. Actually it's the opposite of fun. It's miserably exhausting. It makes my brain ache and my soul itch. It makes me contort myself into something I am painfully not. It brings out the absolute worst in me — the awkward laughter, inappropriate joking, incessant talking and constant second guessing of what someone is saying and if what I have said is socially appropriate.

feature (continued) and a second feature

Not to mention the anxiety-inducing, socialising post mortem. Did I talk too much? Did I dominate conversation for fear of it being taken over and I lose track? Did I offend someone with a comment I didn't have time to think through carefully? Did everyone notice when I just zoned out? And then comes the migraine, the burnout, the shame and the desire to shut down and retreat into my own safe world once again.

I don't have any easy answers. Sometimes operating in the world I'm in requires me to mask. I recognise my privilege to be able to. But since my own diagnosis a year ago, I have made sure that I spend far more time in situations where I'm not required to mask. Knowing now the damage that masking was causing me, I'm even more conscious of where and with whom my time is spent. Sometimes sadly, that means saying goodbye to friendships that you thought would stand the test of time, but if that's the price of unmasking and being true to who you are, then that's a price I will pay.

Masking

by **Katie**

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Masking. I suppose it's the brain's way to protect us . . . to help us fit in . . . to help us make friends . . . to help us conform so that we don't stand out. Yeah, thanks brain, you're so kind but I got this now.

I masked without even knowing I was masking. I problem-solved situations unconsciously and it is only now I am discovering this since my diagnosis in 2019. The reason I say "what?" when you've asked me a question isn't because I didn't hear you, it's because I'm giving myself extra processing time to understand your question. The reason I gently sway from left to right when I am talking to more than one person is to self-soothe because I don't know when to talk. The reason I feel as if I don't know who I am is because everything I am has been dependent on others. I have come to realise that this is why I find it difficult answering questions such as "what are you interested in?" "how do you feel?" "what are your hobbies?" — I just don't know.

Like a chameleon, I can camouflage and the scary thing is, I don't even realise I am doing it. I just know how to be and who to be in order to get by; I don't even have to think about it. I think I subconsciously pick up energies and act accordingly. Another result of masking perhaps? I couldn't pick up on social communication, so my brain said "take the energies instead." It takes its toll, even if I

don't realise I'm doing it. I know this because whenever I'm alone and have time to relax, it feels like I'm hungover and I struggle to function. I call it a social hangover.

If all this isn't complicated enough, I believe I've had a double mask and the second mask comes in the form of my twin sister. I sometimes wonder if I would have been diagnosed earlier if I didn't have my sister to hide behind. As the dominant twin, she did all the hard stuff; making friends, speaking at birthdays, knocking on the door and saying "trick or treat". For the significant changes in life — moving to high school, starting college, moving house, even going to the dentist, I had her by my side and thank God I did! I was more than happy quietly and comfortably smiling and nodding my way through life. It's when we got older and began leading separate lives, I struggled, but that's another story.

I think realising the things we do in order to fit in is a positive step because we can slowly start being ourselves. Educating people about autism so that autistic people can start taking their masks off is important because the exhaustion of keeping up with everyone else's rules and expectations is a full-time job. We need to save as much energy as we can so that we can do the things we love (if we know what those things are). If we don't, we need the energy to find out!

Autism musician

by **Ellie Patricia**

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Hello I'm Ellie. I'm a 21-year-old left-handed musician, I have loved playing instruments and performing since I was 7 or 8 but I've always enjoyed music since I was a few months old. I play fourteen instruments all self-taught. I've never had any lessons. Some of my instruments are quirky and others are well-known.

Performing is my happiness, seeing people enjoy what I do and join in with me definitely puts a smile on my face, as well as other people's faces. When I perform, it really fills me with joy, being a musician also can come with hate and some comments can really get me down, but the good thing about social media is that you can block people and delete comments. Luckily I get more positive comments, which are the best.

Some of my inspirations, who inspired me to be a musician, are: David Byrne from the band Talking Heads because he's also autistic and I absolutely love the way he performs and expresses himself through his movements and he feels the music. George Formby — I absolutely love George, he's a brilliant comedic songwriter and actor and every time I listen to his music I always have a smile on my face — his acting is hilarious too, always makes my day. The Beatles — they inspire me because they were so hardworking and worked hard to get to where they are now and I love the lyrics of the songs and they inspire me too because they are so creative. I'm going to pick

two more people who have inspired me because there's far too many to name, but I'm going to say George Ezra — I like George because his lyrics are storytelling and I can connect with his music, he inspires me because he is so kind-hearted and doesn't care about the fame; he is just happy doing what he loves, which is performing, and I'm the same. Also my inspiration is my grandad who plays the guitar and performs at open mics, as does his best friend Ken — we all share a love of music and enjoy performing.



an article (continued) and another article

The music I play ranges from the Fifties to the Two-Thousands music. I play quite a range from Buddy Holly to The Beatles to George Ezra — people are often shocked with some of the artists I listen to, they always say “you are too young to know this song/artist” but I think music doesn’t have an age because you can discover music so easily and absolutely love it. I’m finding out different musicians and bands a lot recently.

I love it especially when you can support other musicians and they support you back. I’m really grateful for my musician friends and my friends who perform because they are always here for me and we have great chats and can give advice and

tips to each other. Being on the stage always will be my favourite place, whether it is pub stage, festival stage, venue stage or an outside stage I feel free to be myself and I’m proud to be autistic and I’m never going to change because in life you do what you love.

The highlights of my year of 2022 have been: performing at The Leadmill in Sheffield — many iconic musicians I love have performed there — performing at a local charity event — it was an absolutely fantastic day for a great cause — and a local festival which was absolutely phenomenal to perform to a hundred-plus people, and I can’t wait to perform more in the future as I absolutely love it.

Unmasking my creativity

by **Sam Barnes**

I was inspired to write this piece after reading *Freedom* by Tom, and *You’ve become more autistic since your diagnosis* by August in the previous edition.

I started therapy this year, in the hope of working through a lot of complex trauma that I’d been through from an early age. However, what I didn’t expect, was to also find that the relationship I have built up with my therapist has allowed me to see how much I have been masking all these years.

It took me a long time (about six months) but I finally began to feel really comfortable and safe with my therapist, and this allows me to be one hundred percent myself when I’m with her. I started the process of therapy trying to just sit and talk “like everybody else” but was finding this harder and harder (especially the eye contact, that’s tough!).

However, after some trial and error, we worked out how much colouring and drawing really helps me both in and out of the therapy room.

When I’m at home I love colouring in pictures from my favourite tv shows (mostly cartoons!) and films, and I also love drawing in my therapy sessions. It’s a great way for me to express myself and communicate, without the pressure of having to talk for the entire fifty minutes. Sometimes I even just sit and colour in my colouring book in therapy whilst talking; that way I can avoid the sensory overload I get from eye contact.

One of the quotes from August’s piece was “Learning what is authentic to any individual is a process and learning to unmask is often a large part of that for an autistic individual.” I have been burning myself out all these years without even realising I was doing it, but this year has been a positive change for me, as I begin the process of truly figuring out who I am and what works best for me. Through therapy I’m continuing to find things that bring me calm, comfort, and easier ways to communicate with the world, and colouring and drawing just happen to be two of those things!

Masking

by **Katie**

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Have you ever tried to scream in a dream and nothing comes out?
Or tried to run but your legs don't move?
That's how I feel
Stuck, lost, alone
Too "functioning" for people to understand
Too good at masking to stand out
Where do I go from here?
On the surface, everything is in its place
Like my home
But no one ever opens the cupboards
I'm tired
Tired of talking
Tired of justifying
Tired of trying to navigate a world full of noise
Why do I have to try so hard?
I wish I could run into a field and scream from the bottom of my lungs
But I'm afraid someone will hear
You don't see me
I'm a ghost
An imaginary friend
How do I help you understand when you've already decided I'm perfect?
So I'll just carry on
I'll live alone and work with a smile on my face
I'll nod and I'll courtesy
I'll follow your rules so you feel comfortable
Then I'll go home and attempt to untie all the knots the day has created
I don't need help, just understanding
It's not a lot to ask
Let me be unapologetically me
Let me be free
You assume too much
But you don't know me
No one does
Not even myself

How Dungeons and Dragons has been beneficial to me

by Lucas Maxwell

My name is Lucas and I'm a librarian in Surrey. I was diagnosed as autistic later in life, at age 41. This has helped me make sense of a lot of things that have happened to me in the past. I also feel it has helped me connect with my daughter, who is also autistic.

As a librarian in a high-school setting, I have been using the game Dungeons and Dragons for nearly four years. We play twice a week at lunch in the library. I also play online with an amazing group of adults a couple of times a week.

If you've never played it, or never heard of it, it's a game that requires you to use your imagination almost 100% of the time. You roll dice to determine the outcome of a situation that is presented to you and it typically takes place in a fantasy world with magic, terrifying creatures and amazing treasure.

A Dungeon Master (DM) creates the world for the players to interact with. It's amazing because it's completely wide open, creating a sense of freedom and excitement with nothing more than a pencil and paper required.

For me, D&D is a form of therapy in many ways. I have always struggled with social situations, eye contact, small talk and being part of a cohesive group. Taking part in activities like this has always caused me a lot of anxiety.

D&D removes this anxiety for me because everyone is at the table (or online) for the same reason, there are no social barriers to overcome.

With D&D, I am part of a built-in community. We are all there for one common purpose, we love the game, and we love playing in the world that has been created. There is no

awkwardness or social cues to worry about in my experience because through the game I've created great friendships, without the game I wouldn't have had these connections. As someone who would normally shy away from parties or social events, D&D has become my social event or my party (no pun intended). There's no small-talk needed, we all want to get down to business and have fun, roll some dice, slay some monsters, find some loot and build a story together, it's a very unique situation in my experience.

D&D teaches a lot of things, one of them is waiting your turn and being respectful of others, something that our teens playing D&D have tenfold in my experience. You are literally putting yourself in someone else's shoes, a new race, sometimes not even a human being. You have to think from their perspective, how they might perceive the world. You also must be respectful of your teammates' characters' stories, goals and dreams. As shy and introverted as I am, I also can cut people off mid-sentence, or they assume I'm not interested because I won't make eye contact. With D&D I know I'm in a world where the other players' stories are important and need to be worked out and listened to. On a base level, their stories are also crucial to my own survival within the game, therefore it is in my interest to help their character as much as possible.

I am very excited that all of this has culminated in a book I've written that will be published by Facet by the time you read this and is called *Let's roll*. It is meant to be a guide for librarians on how to run games like D&D in public and school libraries. It is one of the proudest things I've accomplished in my career. I sincerely hope librarians get something out of it and I hope you all are able to start a D&D group in your new future!

letter to the Editor

Dear Goth,

I could never understand why people got upset about what I said or did, and still can't. Perhaps we are this way because we lack boundaries (innocent).

Reading John Elder Robison's book *Look me in the eye*, I was reminded of this. Most conversations, when social, are guarded, so say nothing, or try to (heavily defended stance or "How dare you say that!" attitude).

I think we're our own authority. Shallow people are followers — we are self-led, through curiosity.

For instance, if I want to know what the current weather is, I look outside the window but my wife looks up meteorology sites ("XC says it will be raining by ten but the BBC says it will be clear. I don't understand it. Which one is right?" None, as this is *predicted* weather patterns, not the actual weather).

She is surprised that I am practical but this is because I am visually orientated and can see problems to be fixed and can imagine ways to do this (I can't remember names but I can identify faces, years after).

The fact that I don't do things, doesn't mean I can't, just that this is not where my interest in life lies (trying to understand the psychology of what drives other people does).

I am the typical "little professor", scribbling notes in a notebook but not university-educated,

as I found it hard to hold onto a job, let alone study material that would probably have bored me, much as school did.

I was going to send someone an envelope with some of my collage work on the outside and then it suddenly struck me that I could see the connection between the various images and words but I doubted he would. I thought that explains stuff like my language material too and how my approach even to those on the spectrum, drew a blank a lot of the time.

Other people have been judging me as crazy because they couldn't understand me and this is because they simply didn't make the connection to things I did.

My cousin who has always supported me, thinks I shouldn't give up trying to reach people but I fear I have reached my glass ceiling and my audience is minute and specialised (*the Spectrum*, a *Hitch-hikers guide to the galaxy* fansite and Quora, a platform for my philosophy).

Fortean times and *Private eye* sometimes use my material and then there are a few odd individuals: Wrong planet? It certainly seems so and it's a pity I didn't wake up to it earlier instead of wasting so much time, thinking different because I never put myself in other people's shoes.

Paigetheoracle

© Paigetheoracle 2023

If sufficient material is sent in, the theme for July will be **employment, working and finding work** (the Editor has already received a couple of articles about jobs this year), or maybe **hobbies and socialising** (following the article on page 9 about the use of role-playing games like Dungeons and Dragons for socialising). 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, small pieces to fill awkward spaces like this, and art. **Please fill in a permissions form** when you submit something, as all published pieces require a completed permissions form. Remember, if you want to see different content in *the Spectrum*, the best way to change it is to send something in!

Assessment (what I wish I'd said)

by Bea

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illustration © A Bea C 2023

I feel like I didn't explain myself well there.

Okay, so imagine that I'm on the top of a hill and there's a three-sixty view all around.

I start slowly turning, and can see trees, a hillside, a landscape.

But then I get to a section of white, maybe a 30-degree angle of just blankness, a slice of nothing.

So, I carry on turning and then see more landscape, some buildings and so on, blue sky and a bird.

Then I hit a, let's say 10-degree portion of blank again.

That's what it feels like.

I can see and understand a lot of things but then

There are things that bring up a blank

Like I know I'm missing something, because I can feel deeply a gap

And it curls my stomach

But I can't see what it is that I'm not getting.

And I can see when people *can* see it,

And it freezes my chest

But I'm grateful to turn through it all, overall.

Does that help?

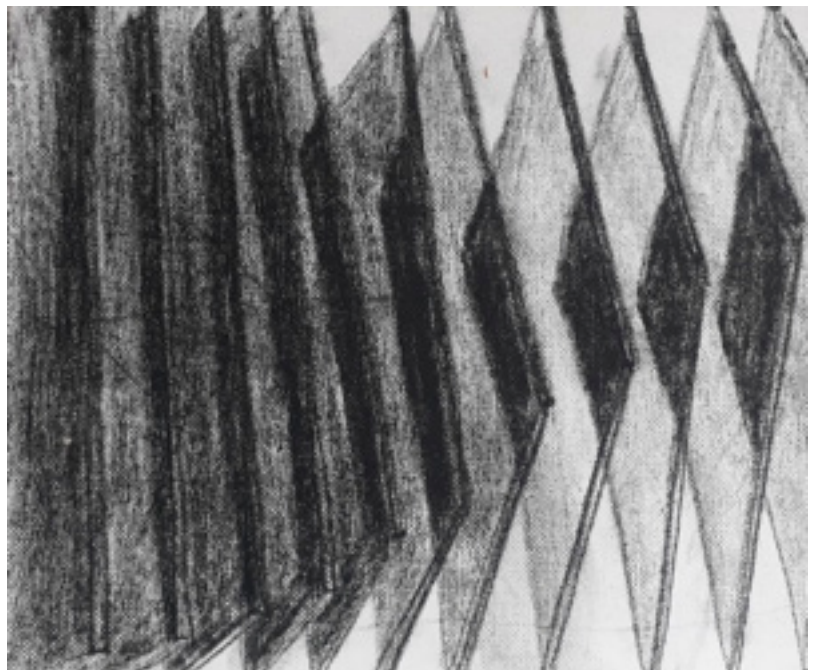
I know you were asking me to describe "friendship" and "love" and whether or not I lived alone; whether I had any partners during my life, if so for how long; if I kept in touch

with old school friends, if so how many; and if I hold down a job, if so for how long.

You didn't ask if I managed to cook and look after myself, or whether sometimes I wanted to live with the curls and freezes.

Instead you asked if I could look after the bills and keep up with things like utility payments.

Bills folded into paper aeroplanes and thrust into the open landscape to track their own journey.



Bonding over Vera

by S Bee

© S Bee 2023

I smiled as I joined a lady sitting on a park bench. “Hello.”

The sixty-something, bespectacled, jean-clad woman looked surprised, but she returned my smile. “Hello pet.”

“This is a ‘Happy to chat’ bench,” I explained. “It’s a new scheme created by the council. There’s certain benches in the park where people can sit and talk together.”

“Okay. I’m happy to chat. I’m Peggy.”

“I’m Amy.”

“Well, what shall we talk about, Amy?” Peggy asked.

I noticed that Peggy had a North-East accent, so I could talk about how I loved the crime drama *Vera* on TV.

I was a big fan. From the footage from *Vera*, Newcastle looked like a vibrant city.

“I wish my ex and I hadn’t broken up.” I blurted it out before I could think about it.

Peggy looked concerned. “Tell me more.”

“We’d planned a future, but he’s taken a year out to

travel. He asked me to travel with him, but I had doubts about leaving my steady job. So I didn’t go.” I blinked back tears.

Dan had been the love of my life. I was still heartbroken.

“Why don’t you contact him?”

I hesitated. “I don’t want to spoil his adventure.”

“If you’re true soulmates, Amy, fate will find a way for you to be together.”

“Will it?” I asked doubtfully.

“I remember when my husband and I were first engaged. He was thinking about joining the army, but I didn’t fancy being an army wife. Long absences from home, me worrying every day . . . then he was offered a job as a trainee car mechanic, so he didn’t join up. I was relieved, but a part of me hoped he wouldn’t live to regret the decision.”

I gulped. “And has he regretted it?”

She chuckled. “I don’t think so, pet. We’ve been married for over thirty-five

years. He has his own business, plus we have a son, a daughter and a granddaughter.”

I smiled. “That’s such an inspiring story.”

Peggy glanced at her watch. “Well, I need to make tracks. I’m due at my daughter’s for Sunday lunch.”

“It was good to talk to you, Peggy.”

“You too. Are you on social media, Amy? Maybe we can keep in touch.”

I brightened. “Yes to both.”

We swapped our SM details, and as she ambled away, she turned back and waved.

At work, on Monday at lunch, I spotted a new recruit, Becky, showing her mobile to a group of colleagues.

“Amy — come and see a snap of my new fella!” she urged. “I met Simon via a dating app.”

I trotted over and saw a picture of a good-looking, smiley guy.

a story (continued) and a poem

That afternoon, Becky was allocated the empty work station next to mine. At break, we chatted easily. To my delight, I discovered she was a *Vera* fan!

I was so glad to find another enthusiast!

“I like Vera because she’s so direct with people,” Becky said.

“Well, I quite like her dress sense,” I put in.

“Especially the hats.”

We giggled.

Becky’s loved-up mood made me wonder if I ought to contact Dan . . . I’d welcome Peggy’s advice again, so at 5.30 when I shrugged on my jacket, on impulse, I raced to the park — but this time, a group of teenagers occupied the “happy to chat” bench.

Oh. Well, I guess I should have messaged her first!

A fortnight later, Becky arrived at work with red eyes.

I flew to her side. “What’s the matter?”

“I think Simon’s —” she began crying, so I led her to the staffroom.

“He’s surgically attached to his mobile. I think he’s meeting other women, using the dating app.”

I handed her a tissue. “Think about how Vera would react. She wouldn’t stand for any nonsense like this.”

Becky straightened her shoulders. “You’re right. I can’t trust him. I’m going to end it via text.”

I nodded. “Good.”

When Becky and I had gone for coffee, we’d talked

about booking a weekend away in Newcastle-upon-Tyne to check out the famous *Vera* locations and the Northumberland coastline.

Hmm, I thought, maybe Peggy could recommend a good hotel?

We’d arranged to meet in the park again this Sunday. We’d only exchanged a few words (and SM messages) yet I’d really warmed to her.

In the park, I spotted Peggy seated on the “happy to chat” bench again.

When she waved to me, I waved back.

I had a feeling we were going to become firm friends . . . and that wasn’t all.

I’d sent Dan a “Miss you” message on social media.

He’d replied, and a few days later, he was on my doorstep, gathering me into his arms . . .

Ceilings and staircases

by Tom

Numbered lists follow me.
One merges into another.
They mesh as I forget
But the numbers stick

To the corners of ceilings, toothbrushes,
And staircases only climbed.
They don’t stick well enough
But well enough they’re mine.

Unmasking your Autism and healing your trauma

by Noah

© Noah L 2023

Content warning: this article talks about trauma and abuse without giving any details of what happened. If you have been affected by any of the content in this article or the magazine, you can visit the National Autistic Society's urgent help page:

<https://www.autism.org.uk/what-we-do/help-and-support/urgent-help>

After a three-year-long journey of cutting off people, acknowledging my childhood wounds, and realizing why I needed to mask, I can now say for the first time, I am unmasked, and that's okay. As someone with Autism, ADHD and OCD, unmasking wasn't easy. During my journey, there were many moments of pain, sorrow, and crying, but now they're not as frequent as they were. If pre-pandemic me could see where I am now, they would feel relief and know that everything was going to be okay, even if they didn't feel it. This is why I wanted to write this article. I hope that either you, or the next person reading it, will see that the path to healing is never an easy one, but recognizing that can be so worth it and unmasking can play a large part in it. If anything, I do not want your journey to take as long as mine did, nor backhand you as much as it did to me. So here you are, a summarized process wherein I break down each part of what it takes to unmask with a little added personal touch; enjoy!

Now, masking can differ depending on your gender. As a male, the ways that I mask may differ from the ways that you mask, but nonetheless, here are some of the ways that I masked or camouflaged my disabilities:

- Fawning
- Overly apologizing
- Seeking reassurance
- Being funny and goofy
- Trying to be outgoing
- Forcing eye-contact

This led to me recognizing why I masked. Unmasking involved me fully reducing all these symptoms. It was a long journey mainly because, subconsciously, I had no idea that I was masking. It was through reading and listening to other Autistic advocates that I learned why I was masking.

Additionally, I found that my mask was often the result of how I responded to abuse from past traumatic events, as a way to protect myself from being traumatized again. I noticed that I never allowed myself to actually listen to what my body needed, I never told people how I was really feeling, and I never acknowledged what was upsetting me. I was taught at a very young age to "tough it out". Anytime I was dysregulated, the effects would stick with me for weeks, with more events piling on top. To finally release my anxiety, I would have a panic attack and then the cycle would start all over again. I discovered that my response to these events was masking and hiding how I really felt. No one, not even my mom, knew my internal struggle for years.

However, hiding and masking didn't help either. Recent studies show that post-traumatic stress disorder can be hidden by the presentation of Autism. This is why PTSD and Autism were thought to be comorbid only in a small percentage, 2-3 percent, of the Autistic population, and this is why I want to be diagnosed for PTSD and I am not alone. It seems to me, researchers are now discovering that a much larger portion of the Autistic community has undiagnosed PTSD. They have

additionally found that Autistic individuals are more susceptible to abuse, and masking is used to counter that abuse (as I did) resulting in that low comorbidity rate.

While I will not talk about the exact events I went through, for two decades I sustained emotional, verbal, and financial abuse. For me, masking was a direct result. What I had to endure led to me masking. I always felt different for one reason or another and masking allowed me to divert people's attention. I found myself highlighting certain aspects of my character and cranking the knob to the max. Instead of being seen as "that ugly, annoying, weird guy", when I masked I was now the "goofy guy", and it worked.

Anytime I would run into people, they would always say, "Hey, it's Noah" or "It's that guy" but that truly wasn't who I was.

To me, unmasking was acknowledging that abuse, acknowledging who abused me, acknowledging my trauma, acknowledging what environments weren't safe for me, and acknowledging what I needed. Unmasking was what led to me healing. The first step I took in the unmasking process was calming my anxiety. Masking is one of the highest-anxiety causes. I wanted to find out the cause of my anxiety. I asked myself: who and what was causing it.

This also coaligns with something called Emotional Intelligence, or EQ. I hope that every Autistic person (and all humans in general) can learn about it. Autistic individuals often have a problem in which we feel empathy, but we don't know how to interpret or express it. EQ is simply asking yourself what I am feeling in this current moment. When I look back there was not a single day that I didn't feel crippling chest pain from my anxiety and panic. Even after diagnosis, I still felt it. It wasn't until I found the book *Un**ck your anxiety* and cut people off that it started to dissipate. This is when I started challenging the mask. For the past two years, that pain has subsided.

This led to the thing that helped me unmask the most, and that was boundary-setting.

Setting boundaries is one of the healthiest things you can do. However, doing that can be one of the hardest things Autistic people have to grapple with. This can lead to an unhealthy give-and-take mentality where an Autistic individual may give everything to a relationship, but the other person gives nothing in return, or takes everything. This is why codependency is very common among masking Autistics. This can lead to us seeing ourselves as a burden, especially when we share our emotions with others. Eventually that turns into shame.

Autistic people live their whole lives with the weight of shame upon their shoulders, especially women, LGBTQ+ people, and people of color. Society does a good job of telling us what is right and what is wrong when it comes to social interactions. Unfortunately, I surrounded myself with toxic individuals that shamed me for what I said or what I did no matter whether it was merited (it almost never was). I probably said sorry at least a hundred times a day and I still over-apologize for the tiniest things. However, I don't do it as much when out in public. This was huge in helping me realize that there was nothing wrong with me and I didn't need to explain myself or apologize to anybody, unless I had actually hurt them. This was a huge step towards self-acceptance and self-healing.

One thing that Autistic people need more of is a support network. When you are masked, you are not in an environment that is safe for you, you are not around people that truly support you. For me, my mom is my support network and I am very lucky to have such a loving, supporting mother, who is self-diagnosed with Autism, and not everyone is that fortunate. We are still looking for other support networks and finding one can be very hard. To counter this, we both have taken up doing things we like, equaling painting, video gaming, and so on. I am now in solitude and I do not care. I do not need to make people happy or comfortable or cater to their needs, and more importantly, I do not need them to make me happy. For those of you who are completely isolated, human interaction is what we need, but we don't need others to validate our feelings. Unmasking led me to understand all of this and because of that, I am now content with who I am, no matter how others perceive it.

Autism and Buddhist practice: how Buddhism can help autistic adults cultivate wellbeing

edited by **Chris Jarrell**

Jessica Kingsley Publishers

ISBN: 978 1 83997 157 0

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book review by **Emily**

Mindfulness has become well known in the West, and Mindfulness-Based Cognitive Therapy is prescribed on the NHS for recurrent depression. However, manualised eight-week courses only offer one interpretation of what mindfulness can be. The courses were designed for a neurotypical client-base and only touch on the flexibilities and depth available through Buddhist practice.

Autism and Buddhist practice is an insightful, poignant, practical and hopeful book. Chris Jarrell has brought together a collection of pieces from autistic meditators and Buddhists. The pieces illustrate how autistic individuals have engaged with, struggled with and benefited from Buddhist practices. The pieces also provide a beautiful window into the thought processes, pains and joys of a wide variety of autistic minds.

Chris introduces the material in a clear and well-structured manner, allowing readers to decide their own route through the book. He clearly signposts how the material can inform autistic individuals interested in exploring Buddhist practice and teachers on how to provide autistic-sensitive guidance. His own writing is clear and easy to follow. His editor's pen has been used carefully to preserve the individual voice in each piece while providing a coherent experience for the reader.

Buddhist practice offers options to be tested against personal experience. It offers options or “many doors” for individuals to try out at their own pace, ideally within non-judgemental communities. Buddhist psychology presents itself as a map, while being clear that it cannot describe the actual terrain of human experience. Practitioners are invited to recognise and acknowledge whatever is happening in their experience, with patience and kindness. This provides space for experience to be atypical.

Communities of any form are still prone to neuro-normative assumptions. Many of the accounts refer to painful challenges with groups and processes within Buddhist communities. There are also accounts of how people have reached out across the neuro-cultural divide. I am grateful for the participants for sharing their experiences and providing insights into what can be done differently. The editor and participants collaborated with Dharma-centre directors, administrators and practice-group leaders to produce *A short guide to autism-sensitive practice* included in the book.

No book is perfect. The editor acknowledges the “absent voices” and the struggle to find autistic BAPOC contributors (that is, from racial minorities). I would have liked the introductory text to have referred to the finding that autistic

a book review (continued) and an article

individuals are much more likely to report “intense empathy” than “lack of empathy”. Reference is made to autistic individuals potentially being good at science, engineering and maths. While the possibility that this is a stereotype is acknowledged, it is a pity that this persists and strengths in areas such as the arts and caring professions are not recognised.

The book was uncomfortable reading in places. Part of the Buddhist path is about change, but where does that change need to take place? Even when an individual talks about voluntary

action, to what extent are they still feeling pressure to mask as opposed to making skilful, respectful, inclusive choices given the mixed neurotypes within their sangha? This is tricky territory and something for on-going reflection within sanghas, ideally with self-learning by neurotypicals and supportive affinity-groups for autistic individuals. Ultimately we are more strongly connected by our humanity than our neurotype, and there is value for us all in negotiating a common path.

I gained a lot from reading this book. Highly recommended.

What I want you to know about autistic women and girls

by **Tracy Smith**

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When you are asked to imagine an autistic person, who do you think of? Someone male? This wouldn't be surprising, as studies indicate that up to five times as many autistic men and boys are diagnosed in comparison to women (National Autistic Society). Indeed, the National Autistic Society put the ratio of men to women who access their adult services at 3:1. Although, through conversations with the autistic community, it appears that women more generally are under-diagnosed. Many choosing not to seek diagnosis for a myriad of reasons. Concerned over stigma “I want to adopt in the future and worry it might be viewed negatively”; worried they may not be believed “people are always incredulous when I raise it”; or facing barriers to healthcare access “they don't believe I have chronic fatigue so why would they help me with this?”.

To compound the issues around under-diagnosis, when autistic women (any person female at birth) do reach out for support, they are likely to exhibit a subtle presentation which often differs from the more externally obvious traits.

The characteristics of autistic females may be overlooked, their interests in books, animals, or teenage bands thought to be typical interests for their age.

As a young child, I read obsessively. I could read confidently at the age of 3. This continued into my childhood, spending so much time immersed in books that I had to hide under the table, in my wardrobe, in the bathroom, anywhere to make sure my books weren't taken away. “Socialisation” you see.

I lived a magical world in my stories and fact books, I loved how you could choose what adventure to dive into, what information you wanted to learn, and how to temporarily sate an endless curiosity. For a time, before I went to sleep, I picked a word from the dictionary to memorise and use in conversation the next day. But these quirks were viewed as academic excellence, a desire to succeed and in a way, yes, they were. I struggle with perfectionism to this day. The intense drive to make sure everything

an article (continued)

looks and sounds “just right”, can easily lead to burnout. It’s an exhausting and unhelpful frame of mind to be in. With this piece, I forced myself to commit only a couple of pomodoro cycles to it and will press send without being fully satisfied. But for me, that’s growth.

Autistic women and girls may appear more social, driven by a greater desire to fit in and feel accepted. They can develop highly compensatory masking techniques from an early age to do this. They may appear quieter and want to please, prioritising other people’s needs above their own. Used to being told they are wrong or have done something incorrectly, they begin to question their own thoughts, feelings, and desires, turning their frustrations inward. This could explain why autistic females are more likely to experience depression and anxiety, and have a greater tendency to develop an eating disorder.

Friendships can often be challenging for autistic people. More so for autistic women and girls who can find it harder to navigate changing expectations and trends, particularly around the time of puberty. Girls’ friendships can be termed “fickle friends”, with fallings-out and disagreements frequent. These friendship features can hide social difficulties that an autistic girl may experience in their teenage years. I remember, as a teenager, not understanding why everyone wanted a tiny sports rucksack, why it would be desired. To me, these bags didn’t have enough space to carry all your books, so you had to have another carrier bag which was cumbersome to transport. But, wanting to fit in, I bought one anyway, secretly hating myself for giving in, but knowing I had to or risk ridicule. I took this mimicking to its peak when my best friend at the time changed their style completely. I went out and bought the exact same outfit I had seen her in, thinking it would be a compliment. No reader, as you can probably guess, it wasn’t. Knowing the boundaries of what is acceptable, and what is not, is hard for me to work out. It’s probably why I find human behaviour so fascinating, choosing to study this for my masters. I guess it’s easier for me to approach this from an academic standpoint rather than a

personal one. Safer that way, less hurt.

While I now feel secure in my own interests and tastes, as a teen living through school days which felt a lot like *The hunger games*, it was a difficult time. As part of my work, I support autistic students at university through specialist autism mentoring. I help them get the most from their university experience, giving them the tools and strategies I wished I had when I was studying at undergraduate level.

It’s a huge privilege to enter their world, hear their vulnerabilities, and be with them on their journey at such a crucial time in their lives. Knowing that they have someone who thinks and perceives similarly to them can be transformational, with much of my work supporting them to develop and maintain a positive autistic identity.

So, what do I want you to know about autistic women and girls? We are out there, sometimes invisible, but doing our best in a world which doesn’t always work for us. Please be accepting of difference, be inclusive in your approach, and strive to understand the qualities that make us all unique.

Recycled notice

Due to an unexpected change of printers, *the Spectrum* is not able to display the FSC (Forestry Stewardship Commission) logo that confirms that the Spectrum is printed on recycled paper.

Getting certification for the paper would have delayed this edition even more, which I did not want to do.

This copy of *the Spectrum* (if you’re reading the paper version) is still being printed on as close to fully recycled paper as I can find at short notice, and I shall try to keep to recycled paper in future, Editor.

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 National Autistic Society and readers' subscriptions. We welcome submissions on any topic from people across the whole of the autism spectrum.
- 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) 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. If you do not want your review to appear in other National Autistic Society publicity about that book, please make this clear.
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- 10) 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.
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The joys of bread-making

by Nick

There is nothing like the pleasure of returning home after a long cycle ride to the smell of freshly baked bread. I live in a rural community, and we lack a local bakery, so I use a bread-maker. It took some time to get used to the machine and I made the mistake of using the recipe for a small loaf when it will only make two larger sizes. When I first brought the bread-maker to bake French bread, I was expecting it to make a baguette as this is how I think of French bread. I could not understand how this would work in a small, rectangular box. I honestly thought I would return home to a baguette sticking out of the lid! I was somewhat disappointed to learn that it simply makes a French loaf, which is very nice but come on, the designers missed an opportunity for an exploding baguette!

My first attempts, while edible, did not rise enough. I did get better but struggled to get the bread out of the tin after baking. My little gentle taps did little other than to distort the pan, which made the issue worse. Having dyspraxia is such fun at times! I tried using a knife, but this scraped the non-stick surface, and I considered

using cutting tools at one stage! I also managed to damage the seal which let the water out after adding the ingredients, but of course, I was only aware of this hours later when finding a tray with a small amount of breadcrumbs at the bottom. I should have sent a sample to Porton Down just to see what they would have found. No, the trick is to simply turn the tin upside down and tap it in the sink and let gravity do its thing.

As much as I liked the French bread, I was worried about my diet and so changed to making brown bread to eat more healthily. This took some experimenting, but now I am making nice bread. I accept that it does not look perfect but when you cut a slice, the smell is wonderful and makes my tastebuds tremble. I did try wholemeal but this ended up in a small, rather wet bread. I should have sold them to my local health shop as organic sponges, given how much water they had soaked up. After all this, I love sitting down to eating some bread with jam and butter knowing it will taste of bread and not the poor examples I have bought in the past where I would have been better off eating the wrapper for flavour.

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