

Produced by and for autistic people

# The Spectrum

Edition **119** July 2024



National  
Autistic  
Society

# The Spectrum

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*The Spectrum* is run by and for autistic adults (although some parents subscribe on behalf of their under-16s). 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.

*The Spectrum* is available at

**[www.autism.org.uk/theSpectrum](http://www.autism.org.uk/theSpectrum)**

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

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

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

The purpose of the magazine was to develop a publication that was truly the voice of the people it was aimed at. The magazine has also provided work experience for those who have held the position of Editor and Sub-editor. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds, John Joyce and 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 a group of original readers. This was suggested by **Anna Kaczynski**. The name *the Spectrum* was suggested by dozens of people and chosen in an online poll in 2018.

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**Please send all correspondence and subscription requests to:**

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and follow the link to the submissions form.

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

**Welcome** to the delayed July edition.

We are sorry for the delay to the magazine this year. We are hoping to have the next issue (October) with you (wait for it) in October.

We hope you enjoy the great variety of articles, poetry and artwork. This issue is on the theme of diagnosis to coincide with our new advice and guidance pages on diagnosis on our website.

We also want to remind you that the October issue will have a few design changes to it. We want to bring it in line with the current National Autistic Society branding. There will also be no suggested theme for the October issue and we welcome submissions on any topic of your choosing. Remember to complete a permissions form for your submission, as we can't publish anything without it. Please submit work here:

[www.autism.org.uk/the-spectrum/submit-work](http://www.autism.org.uk/the-spectrum/submit-work)

Yours,

Fiona and Charlotte

**the Editors**

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# Unveiling the spectrum: navigating life as a young, newly-diagnosed autistic woman

by Georgia

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Seeing the word ‘autistic’ written on my diagnosis papers hurt me. Throughout my life, I’ve experienced trauma which has resulted in a few mental health diagnoses that I’ve received treatment for. To me, when I first saw the word ‘autistic’ it felt like another label, another thing wrong with me. It wasn’t like when I was diagnosed with a mental health condition, where I was given a recovery pathway of therapy and medication. I was told I was diagnosed as autistic and that was it – I had to navigate my response to that diagnosis myself. After carrying out some research, I found there were options for support groups and weekly sessions at my local Autism Hub. But as I’m a rather particular introvert, I knew that they wouldn’t work for me straight away.

Nobody knows me like I know myself. I knew that I wouldn’t respond well to working with other autistic people, and I also knew that it wouldn’t help me in my process of accepting my diagnosis. I tried doing vigorous research and for a while, my autism diagnosis became a special interest to me. But that soon fizzled out when I was trying to understand absolutely everything about myself through articles and statistics – which just simply wasn’t practical. There is quite a lack of resources when it comes to post-diagnosis life for autistic people, no matter what they identify as. Everyone knows that there is also a lack of research on adult autistic people because it is only now being ‘normalised’ to get diagnosed later in life.

As a female, when I was younger, my autistic traits were silenced throughout my compulsory education due to my strong performance in schoolwork which included exams. Despite always knowing that I was different to my family, I was

‘Just Georgia’. Even if that meant that I would ‘turn off’ during social interactions, I couldn’t cope with loud environments and could never keep friendships for very long due to my black-and-white thinking. It was only when I got into a mental health crisis over a year ago, that my autistic traits were highlighted in an assessment and that was when the process of diagnosis started.

I got extremely lucky in my diagnosis process. Everything was very quick, and I was diagnosed within a year after the process started. I was also constantly met with people who were determined to help me and get me the diagnosis that was needed for me to move forward in my life. The process for the diagnosis wasn’t easy, but why would it be? You’re practically unpicking everything that is ‘wrong’ with you, as an explanation to why you struggle in different circumstances. It took a couple of months post-diagnosis to finally come to the decision that I needed to embrace my autism diagnosis. It certainly won’t be disappearing anytime soon, and I can use it as my ‘superpower’.

I also got lucky with the timing of my diagnosis where I was recommended to be a participant in research with a couple of Russell Group universities.

The research was extremely helpful in coming to terms with my diagnosis and it allowed me (now that I was feeling ready) to speak to other autistic adults like myself. There were weekly sessions for six weeks and each of them was themed with different areas of information surrounding autism. It helped me to understand all the different terminology, understanding the laws that can protect me with my disability as well

## an article continued and another one

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as understanding that it is okay to be autistic.

I'm grateful for the people that I've had around me through the process of my diagnosis. I know that not everyone has access to what I've got, so for that I'm extremely lucky. I simply wouldn't have gone ahead with the diagnosis if it wasn't for the determination and support from both my mum and dad, as well as my partner. Navigating my life as a newly-diagnosed autistic female has

certainly already had its ups and downs (and it has only been a matter of months)! But I want to assure anybody who is reading this, that is in the process of going through their autism diagnosis, that it'll be okay. Once you allow yourself to process the information at whatever pace you need to, you'll learn to understand yourself and your needs one day at a time.

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## The Unanswerable

by **Holly**

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“How do you feel now?” is the question I was asked by many, upon receiving my diagnosis letter of autism. Yet it was the exact question I knew I couldn't answer, at least not in the way people wanted me to, or were expecting to hear. I could fake a smile and say ‘it changed everything, I feel like a completely new person!’ but in truth, I felt no different, completely neutral. I questioned myself for a long time as a result of my lack of emotional response to the diagnosis, at times even asking myself if I really was autistic, until eventually I realised what I was experiencing was completely normal.

It's normal to feel like nothing has changed, it's normal to feel like everything has changed, but it's also normal to neither know how you feel, nor feel at all! Just like being on the spectrum is different for everyone, how we process a diagnosis will be different for everyone too.

The diagnosis has helped me in many ways. It has allowed me to piece together more easily my past in a way that showed a clearer picture. Bringing blurry memories more easily into focus, seeing past experiences and interactions through different lenses, it has allowed me to be heard at times when my voice alone just wasn't loud enough. It was an explanation to a seemingly unanswerable question I'd held for a long time.

But to any others who have experienced a similar feeling, it's okay! Getting a diagnosis can be a stressful process, so it's completely acceptable to let yourself and your mind rest after it, allow yourself to process it in the way you need to, there is no ‘normal’ way. There is only the way that works for you.

## The power of positive late diagnosis: embracing autism in adulthood

by Johanna

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Autism is a unique way of processing the world and, in females like myself, often goes undiagnosed until well into adulthood. The journey to recognition can come with its own set of challenges, but for many adults who were diagnosed later in life, the discovery of being on the spectrum can be life-changing in the most positive sense.

In my early 50s, I received my autism diagnosis. Looking back, I had known for some time that I was different in my way of thinking and interacting with the world. I often felt isolated, both as a child and as an adult, feeling I never really fitted anywhere. I often fell out with people as I tried to stand my ground and never held a job down for more than a couple of months. I had seen so many different people getting mental health labels from borderline personality disorder to schizophrenia, none of which I could identify myself with.

I watched a programme on what was then termed 'Asperger's' when I was in my early 30s and it resonated so much with me that I just knew that was what I was. However, I struggled to fully embrace my identity as an autistic person. It felt like living with imposter syndrome. I found it difficult to call myself autistic without an official diagnosis. Saying I thought that I was on the spectrum but not having a diagnosis was difficult. After all, who would believe me? I went to my doctor's and he agreed that I may be displaying some traits. However, it took me another 20 years to finally find the right route to getting diagnosed.

Receiving my diagnosis was a turning point that empowered me in ways I never imagined. Suddenly, my experiences could be defined and led to a common language to support my own understanding. It wasn't the permission I

needed to finally call myself autistic; it was the understanding of how I fitted, how I processed the world. Although I know I saw and interacted with the world differently, it took speaking to people who understood to fully understand myself. It gave me a language to start to unpick why I behaved in certain ways. Why particular situations left me so drained that it took several days to recover. I started to acknowledge the definition of masking, a term I had not heard of before. It validated what I had felt all along, providing a sense of belonging and self-acceptance that had eluded me for years.

One significant advantage of my late diagnosis was the paperwork it gave me and avenues previously unavailable when navigating certain interactions, especially with figures of authority. Having a diagnosis provided a tangible validation of my experiences, making it easier to communicate my needs and have them acknowledged and respected. As a person of a certain age, my visits to the doctors have become more regular as things start to go wrong. My diagnosis has helped because now I can ask them to not touch me, or if they do, to make sure it is firm. I can ask them to ask questions one at a time and not to ask either/or questions. I don't have to look any further than my diagnosis for an explanation for them. Previously I was treated as if I was being difficult, now I still get the occasional problem but it is no way as bad as it was. It has also made it so much easier for me to ask for my husband to accompany me as my advocate and support on these occasions.

Reflecting on my journey, even a few years ago, without an official diagnosis, my experiences and struggles were often met with scepticism. People in positions of power or authority required concrete proof to believe and accommodate my

## an article continued and two poems

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needs effectively. My diagnosis bridged that gap, leading to greater understanding and acceptance from those around me. I am not saying it was a magic wand – I still come up against ignorance and misunderstanding – but it helps. This does seem wrong to me: you do not have to prove you are neurotypical so why should you have to prove you are neurodivergent? I need help with many things and it shouldn't matter if I am 'different', all that should be of concern is that I need help. After all, neurodiversity and disability are not always bedfellows and when they are it is not always a clear and straightforward case.

I have a newfound sense of self-awareness and acceptance, embracing my autism. Each day brings new opportunities for growth and self-discovery. I try to navigate this neurotypical world from a new understanding of my uniqueness.

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### Today's big session

by **Elouise**

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Apprehension, tension,  
I never knew this day would feel,  
Like this.

Confession, today's big session,  
I finally get to show the world,  
My real me.

Questions, more questions,  
Exploring the past is painful, though,  
It is done.  
Lessons, adolescence,  
You know, you're different,  
You hide yourself, and your mistakes.

In session, in question,  
20 years, of not knowing, yet,  
Here we are, at my autism assessment.

In the discourse around late diagnoses of autism, there are pros, cons and a neutral standpoint. While the journey to recognition may come with challenges, the power of a positive late diagnosis cannot be overlooked. It can provide individuals with a sense of empowerment, belonging and understanding, profoundly impacting their lives for the better.

So, if you find yourself on a similar journey, remember that being diagnosed late can be a transformative experience. Embrace your uniqueness and let the world see the incredible individual you are!

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### Day zero

by **Benjamin**

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Forget what you learned and start over,  
even your reflection was wrong.  
Each day, you practised your smile and composure,  
yet your friends never heard the same song.

For years, you bent to wafer-thin moulds,  
tilting your edge just to fit.  
You followed their eyes like a fire in the cold,  
and buried your thoughts in a pit.

You now have a label and a neat little box,  
to nestle your shadow within.  
For all that you were fell away like old blocks,  
and a stranger is wearing your skin.

You turned 26, you laughed, and you cried,  
you fought just to walk out the door.  
But now you feel like all that was a lie,  
because no one ever noticed before.

You wish you could talk to that boy in the dark,  
and guide him on his way to meet you.  
Because now, you no longer know who you are,  
or even which memories are true.

## A little sooner

by **Rebecca**

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I thought as a child  
that adults knew  
everything.

I thought they saw  
past lies,  
and would correct my flaws with an  
encyclopedia of knowledge  
won by years of experience that  
I didn't have.

I thought I was flawed.  
I rocked and smiled,  
in all the wrong ways.  
I bounced on shoulders and played with toys  
past their recommended age.  
I was unable to tie shoelaces  
Or give a stranger my name.  
I was happy,  
but in all the wrong ways.

And even when my wrong smiles  
turned to tears,  
and on my label the adults wrote  
ANXIETY and  
HYSTERICAL and  
NERVOUS ABOUT EXAMS,  
underneath, there was still  
me,  
waiting.

To be told.  
To be old.  
To find out what was wrong with me.

And if you had bothered to  
look and  
see and  
question what might have  
been really hiding underneath  
all these masks I wear, oh so  
perfectly,  
maybe, just maybe, I might  
have been me  
a little sooner.

But, instead I grieve  
what little old me could have done,  
if someone had to said to me  
a little sooner  
that pesky little word  
Autistic,  
instead of just leaving  
me be.  
Because underneath there was  
nothing wrong with me.  
Now I can see,  
there was just me.



## Diagnosis: a new start

by Louise

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Diagnosis feels like a new start for me. It is very new – only in recent weeks. I have felt relieved and liberated after four decades to have an explanation that fits so many moments of my life. I have been able to take back all those memories, reflect upon them again with a more compassionate heart. Not only for myself, but also for those in the moments with me. The new dimension of understanding colours in all the gaps, where confusion, frustration and anger of others (and later alone, my own) used to be.

It is a great weight lifted, and although I feel more aware of the challenges, even a little raw, emotionally, at all these memories flooding back, there is relief. Because though I had let them go, they were like pieces of a jigsaw I threw away, without knowing what the picture was meant to be.

I see the full picture now. I know its edges and the depths of its colours, what objects and shadows, what light and textures play across it. I no longer need the jigsaw pieces. I have the big picture, whole and in front of me. My life so far. It is a fresh start, a new beginning. It feels tentative and exciting, like shyness and burst-out-loud laughter combined.

Much as other milestones that bring with them transformation... this feels just as seismic. Yet the transformation is only my response to being autistic. My awareness of it has always been there. It had no name, all these years, though it was there; very much in my responses to others, the world around me, my way of being. It has been with me in all those moments. Only now I know its name.

I had deliberated for a year whether to bother with a diagnosis. I felt certain I was autistic and I

had heard stories of painful and protracted wait times, unpleasant talks and insensitive approaches to the identification process. I am grateful mine was a positive and supportive experience.

Now that I have been identified as autistic, I feel liberated. I had shied from the word at first, not wanting to take it on, in case it didn't really belong to me. Yet now I know it is part of who I am, I am happy to share it with others. The community is so kind. It feels good with one word to announce that I may think, speak and respond differently. Though I still have something to say. I may need a moment to orientate myself, though I still have something of value to contribute.

I had been working on changes and adaptations to the home and my schedule, how I create and go about daily living tasks. It feels like the identification/diagnosis has reinforced my resilience. I am used to finding my own way to do things when the way others take does not work. I quite enjoy the creative response to such situations! These choices feel validated; because they are a kindness that moves in both directions. They empower me to show up, create and interact in the way I do and that contributes something unique to the world – as we all do.

I hadn't realised how much it would mean to me. And though it is still a little vulnerable, the unveiling of my autistic self, it feels familiar - like a coming home after a long holiday. The diagnosis has helped me to feel more confident. It has given me confirmation that things I believe are best replaced with alternatives or adaptations, can be let go peacefully. And other things, that I want to step into, embrace or expand, are to be encouraged.

## My diagnosis and new start

by **Matthew**

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On a Friday afternoon in February, I was sat with my wife in a small, disused room waiting for the results of my autism assessment. This was after an unplanned visit to the nearest coffee shop as we'd arrived at the appointment an hour and half early thanks to my anxiety and a deep-rooted abhorrence of being late. My leg was bouncing up and down, I'd had a nosebleed in the coffee shop, my t-shirt sat firmly above my nose. I had convinced myself that I had failed my autism assessment. Telling myself that the assessor, dressed in blue scrubs, would simply say, "You are not autistic, you are simply odd." I had been thinking that almost every day since I sat the assessment three months previously. My wife was trying to reassure me that even if he did say I wasn't autistic, which she said was highly unlikely, it was going to be alright. Was it though? Was the answer to this question in any way going to answer the questions I had about myself and solve the problems I'd been having all my life? I had my doubts.

The assessor held out an A4 envelope which contained: the results of our interview, the multi-disciplinary team (MDT) review and all the background information he had found out about me. He smiled, my leg twitched, and I was looking anywhere and everywhere that wasn't at him. I was incredibly nervous, and then he said, "There is significant evidence to indicate that you are autistic." The weight of his words fell as flat as I felt. As he went through the report I counted the number of computers in the room, two. The number of empty binders, four and chairs, five. I drifted in and out of the conversation, monosyllabic in my responses and after several prompts, I asked, "What flavour of autism am I?" He said we don't use terms like 'Aspergers' anymore but that autism spectrum condition was an umbrella term. I had a lot to learn. What was I thinking?

I am not an emotional person but what, if anything, was I feeling? Was I swept away by a tsunami of relief? Did every faux pas and every misunderstanding suddenly make sense?

The answer, annoyingly, was yes and no.

It was a relief to know that there was an explanation for my struggles – not an excuse for them but an explanation. This 17-page report meant I should be able to get help at work and that with support I might be able to break my own mind-forged manacles and cycles of failures. It meant that I had a definite avenue to explore in order to get the help that I needed.

Alternatively, it meant that I was, officially, disabled. I had a disability and there was something 'wrong' with me. I must stress here that this was my initial reflex reaction. There is nothing 'wrong' with being autistic or having any neurodivergence and I knew this because my perfect son is autistic, and I had spent many years teaching wonderful teenagers on the spectrum. This reaction related to me, and my crippling low self-esteem likely fuelled it.

I spent a lot of time unsure of what it is that I need and unsure about where my difficulties lay. I grieved for the person I thought I was and had fleeting feelings of guilt at passing this down to my son, who reassures me that he actually loves being autistic. I wished I shared his view. I worried about this new label I attached to myself and how I would be perceived by neurotypical people, my family, my friends – how would I tell them? The stigma that is sadly still attached to neurodiversity weighed on me as did the emotional weight of the news. I wish it didn't, I wish I had an overwhelming feeling of relief and positivity but that wasn't to be. My initial reactions to most

things in life have always been negative and it wasn't until I received my diagnosis and began my journey of self-discovery that I started seeing things in a more positive light.

My initial response may be due to the fact that I was being diagnosed in my forties. I'd read that late diagnoses are harder to accept. Either way, it all began to weigh on me heavily. Finding out I was not what I always thought, I was actually hurt. It is hard to explain in logical terms but until it was suggested that I may be autistic, I had never thought about myself in those terms. I was 'normal', whatever that is. Sure, I was eccentric, quick-witted and permanently had my foot in my mouth. But then so are a lot of others.

The words, 'what if' came to my mind over and over again. What if I had been supported throughout my various careers or studies? What if I had known that I found reading people's body language difficult? Would my life have been different? What if I knew that I struggled in loud office spaces or doing 'boring' work? What if? It took quite some time for me to finally come to terms with my new identity. I didn't want to define myself as autistic any more than I would want to define myself as depressive. It took me far too long to learn that, essentially, autism is how I am, not what I am.

However, the process of diagnosis has allowed me to see my whole life under the banner of my differences. It's allowed me to see my past in a kinder light. No longer had I failed, no longer had I been the one who was just odd. I was just someone who didn't know about the support they needed. And through discovering what my needs are, what support is available and having the confidence to speak up and ask for help, I now see myself in a much more positive and hopeful way.

I am training with a coach who specialises in neurodiversity, and she is helping me identify my needs and providing tools to combat them. Through this work I can see that, with support, I can be successful. And I can take credit in what I was able to achieve before my diagnosis without

any support. I have been married for a long time, I have a wonderful family and have been successful when I have been focused. The diagnosis has allowed me to give myself a break; instead of looking back and being so hard on myself, I can look back and think that I actually did really well. My diagnosis allows me to say, 'I need help', 'I deserve help' and 'I have the right to have help'.

Although my diagnosis did not answer all the questions I have about who I am and why I act the way I do, it has provided a framework for this investigation. Because I am a later in life diagnosis, residing firmly in my forties, it has given me the chance to understand myself in a way that I would not have done before. It does not mean that I no longer experience challenges, but it does allow me to take a step back and ask what support I need so I can overcome them.

I may spend the rest of my life figuring out my strengths and weaknesses and they may change over time. But I know I will now always be advocating for people on the spectrum, my son, my wife and finally, myself. I am finally proud to be part of the neurodiverse community and will be one of the voices speaking up for the world to 'accept, adapt and advocate' for all neurodivergent people. With the right support, knowledge and understanding we can achieve magnificent things. It is receiving my diagnosis and gaining a better understanding of myself that has allowed me to do this.

To anyone thinking about getting a diagnosis or struggling with their diagnosis, we are here for you and although it may not feel like it, all will be well.

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## My diagnosis

by Simon

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Three years ago today, I was finally diagnosed with autism, a few months shy of my 40th birthday. I'd spent at least that amount of time waiting for my answer and finally I'd got it. One psychologist, one speech therapist and nine hours spent answering questions later, all doubt was removed and I got my 'Yes.'

No-one really 'becomes' autistic of course. You have that status from the moment you are born, and it remains with you until the moment you die. Present figures estimate some 700,000 people in the UK to be autistic and many will be undiagnosed – as I was, for the majority of my life. That figure could well change as our understanding improves.

Here are three things I have learned since I was diagnosed:

Firstly, being autistic takes time to process, especially if your awareness of it comes later in life. It doesn't matter if it's an 'official' diagnosis or if you self-identify, which the majority of the autistic community (myself included) regard as entirely legitimate (don't get me started on waiting lists for official diagnoses, and that's just in the UK).

It takes time. Why? Quite simply because you are not the person you thought you were. There is an underlying 'something' which is different about you and this will take time to explore and to understand. You will inevitably find yourself thinking back over the life you have lived so far, recalling vividly moments when you struggled to be understood, when you found yourself becoming frustrated, upset or just simply overwhelmed by the world.

Autistic people often have excellent long-term memories and superb factual recall, so we can remember in great detail what happened and how we felt about it. Some of this is painful stuff and it can take time to unpack. Be patient. The insights will come – you just have to let them and be willing to process them as they do.

My journey is still ongoing, and even last week I had a powerful insight about why I had acted in a particularly destructive way when I was in my late teens and early 20s. I realised my overly rigid view of the world had partly been to blame. It was painful to realise, but far preferable to my previous view, which was that I was simply a 'bad' or 'failed' person. Be gentle with yourself.

Secondly, not everyone is interested. I know, I know – you may have waited years for the diagnosis or find that when the penny drops, you just want to run around shouting it from the rooftops, sharing every last detail with anyone who manifests even the tiniest bit of interest. Many of us info-dump at the least opportunity, as many of my friends and colleagues will attest. Topics I have subjected them to over the years include: the number of drafts of the Magna carta (don't people realise there wasn't just one version in 1215? No? Why not?!); various bits of cult TV (Dr Who especially); early Roman emperors; mythology; Batman; the plots of graphic novels; the laws of thermodynamics (I was going through a phase); and Lego collecting. The latter is very much ongoing.

So yes, we info-dump. And woe betide anyone who gets in our way when we're in full flow. Having autism as a special interest seems somehow ironically appropriate. After all, what could possibly be more fascinating than talking

about our own minds and the way they are wired? The trouble is, not everyone shares our deep-seated need to talk about these things. I have broadly divided this into two categories:

The first is people who are perfectly nice and understanding and most of the time either do or would try their best to be patient, but don't always manage it. Fair enough. We can be pretty off-putting if we're really off on one and for those of you who listened politely, even when we were boring you to tears, thank you. We appreciated you listening even if we didn't know how to express it or even that we should.

The second is people who really do not give a damn under any circumstances. At best, they are indifferent to the fact those on the spectrum are trying to get by in a world not set up for them, and at worst, they are unhelpful or actively hostile. They may question you. 'You're not really autistic, are you?' they will ask. Their incredulity may be sparked by any number of things including (but not limited to): having a job; driving a car; having your own house; having gone on holiday by yourself or with friends – actually, having friends in the first place; and (let's hear it for a particularly persistent one) being assigned female at birth (AFAB).

In my case, there's a number of things which go against me, not least that I used to work as a journalist. (Horror of horrors! You've interviewed people and everything! Pah, you absolute fraud, etc.) By the way, anyone who thinks journalists simply cannot have autistic people among their ranks is urged to read Laura James' excellent book *Odd girl out* – and my own book, if it ever does get written.

Before we get too sidetracked, there are plenty of people who are simply not interested in facts or

even insights and would prefer to live in a world where outdated stereotypes rule. There's not much you can do about this kind of thinking other than leave them to it. And yet, it feels so unsatisfying and itchy somehow. I can only speak for me in this regard, but I love learning new things and discovering when I'm mistaken about something, and I know others do, too. Not everyone feels the same, and sometimes the reminders can be painful.

The third thing I've learned relates to the first and it's this: adjustments will have to be made. Ever wonder why you go to certain types of events and always come back feeling exhausted? Or why certain textures, noises, smells or intensity of light makes you want to scream? Well, now you know. More importantly, you can do something about it. Invest in those noise-cancelling headphones, buy yourself some good sunglasses, plan your days to maximise the things you enjoy doing, whatever it takes. But you are not the person you thought you were. You are someone else and that's absolutely fine. In fact, it's better than fine – it's fascinating. For all the difficulties that being autistic can bring, I am convinced it has given me an intensity of joy and pleasure in the things I love in my life which I would not otherwise have. I would not change it.

If you are awaiting your own 'official' diagnosis, I wish you all the best and hope it will bring you the answers you seek. To paraphrase something I wrote a few years ago, having a diagnosis is unlikely to change your entire life – it hasn't exactly changed mine, but it has made me feel happier simply to be me.

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## Diagnosis

by Nick

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Like so many of us here, I was diagnosed late at age 38. Of course, this led to a life of being misunderstood and not feeling connected with the world around me. I spent years being accused of being a fussy eater when, in fact, I was struggling with new textures and flavours but lacked the knowledge and understanding that a diagnosis brings. I still get reminded of an early birthday party and accused of being naughty when I was simply experiencing a meltdown. Simple when you know about these things, but if only I knew then!

But a diagnosis can come with family issues and a lack of understanding. This was quite hurtful when seeing other families rally around a loved one, with support and knowledge. Possibly a diagnosis could come with autism training for families instead of handing out an information sheet to the newly diagnosed? It is great to find out you are on the spectrum and to finally realise that you were different for a very good reason and that this is okay. But I think it would be a good idea to educate and support the family too as they need to adjust and know how to best support a loved one.

I do not wish to dwell on the negative but focus on the many positives. For a start, I get to meet so many good people on the spectrum. Online and at The Autism Show. It is from meeting people that I have learned to relax more and stop masking so much. To wear ear defenders when out as well as a sunflower lanyard. I also wear some funny autism t-shirts which always make people laugh when they read the text. Humour is a great social leveller and why not spread some joy?

I joined a local cycling club and they have been so supportive and understanding. I often struggle in noisy cafes but no longer shy away from covering my ears as they know why I have to do this. One kind member offered to bring me some specialist ear plugs to help. A diagnosis also helped me by

discovering I have dyspraxia and struggled with this for years, thinking I was clumsy. I cycle up hills fast but going round corners is not enjoyable for me. I have to brake hard unlike other riders who can take the racing line to go faster – sigh! Again, knowing about this helps.

I recently undertook a re-paint of my Land Rover after many years of work to get this far. I was put off by my poor co-ordination but then thought ‘just get on with it’ and accept I am not going to make a pristine job and as long as it looks okay from two paces away then that is fine. And it was – many people have commented on how well it looks. This really gave me confidence to carry on and I plan to do another coat and varnish it this week, weather permitting.

All of this knowledge and understanding has allowed me to gain more confidence and to travel more. I do enjoy visiting London and recently attended a sensory performance of the play *Nye* at the National Theatre, which was a big step for me. I had a slight meltdown at the start but was able to make use of the quiet room so could enjoy the rest. I took a good friend to a local cinema screening as I enjoyed it so much. I have to book assistance to use the trains but this is all part of the fun for me – why struggle? Have you seen the ticket prices? Exactly! In fact, roll out the red carpet for me, never mind the buggy service. I want it all! Considering what we put up with, we deserve it.

If you have just been diagnosed, then welcome to a wonderful community of like-minded people. Yes, it can be quite confusing if you have felt different without knowing why. But now you can build on this knowledge and hopefully find peace and gain confidence. Autistics are so humorous, generous and kind. I would struggle to list the many examples of this. I hope that you too meet new people, join groups or whatever you want to do and at your pace.

## A diagnosis is a journey

by **Rune**

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The day I received my diagnosis, I thought I finally had my answer. I thought the world would be clearer and everything would make sense, only to realise that a diagnosis was just the name of the journey I was on.

Autism was a locked gate, and the diagnosis was the key to opening that gate, and as I venture further down the path, I am faced with obstacles, diversions, struggles and challenges. They say the first obstacle is acceptance, but acceptance is not an obstacle, it's a state of mind, it's an attitude toward knowledge.

I know I am autistic, I cannot change that fact, but do I choose to acknowledge what I am and embrace it? Do I acknowledge it and hide it? Or do I ignore it and hope nobody notices?

And it's not just our acceptance of ourselves that we have to face, but also the acceptance from others, whether it be close friends and family or society itself. I was lucky that I had a mother with an open mind who embraced me for who I am and loves me unconditionally, and friends who were also on the spectrum. However, I faced a devastating flood of hatred from online trolls and forums who would call me offensive, vile and disgusting things, communicating in a threatening manner and it all became too much for me mentally.

I found it difficult to focus on my mental wellbeing while faced with such hatred. I had already gone through a childhood of bullying and abuse from others for things I have no control over, and now at 16, just starting college, I was confronted by it again. So, after leaving college, I also left the internet and I focused on me.

Now I realise the first obstacle is the decision to put yourself first. You can still focus on your family, friends, career and education, but without

balanced or positive mental wellbeing, those things will become more of a task and a hindrance and they will fall apart. Before I got help for my mental health and started treatment, my relationships strained and dissolved, my grades suffered and I was a stranger to my family.

When I finally put myself first and focused on my mental health, I could see why all that was happening, I could see why life was unnecessarily difficult - because it doesn't have to be. The first step is you, and your choice to make that first step.

And the journey is not easy, that is why support is essential. You do not have to do it alone, and it does not have to be so difficult that you can't imagine facing the next day.

A diagnosis is a journey, do not do it alone.

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## My new start

by **Tessa**

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I didn't know I needed a diagnosis until I received one. I had lived my life with silent struggles and a hyper-sensitivity to the world around me. All of my daily difficulties were related to my sensory experiences and routine needs. I owe my quality of life to my medical team that advocated for my evaluation. My diagnosis urged me to increase my supports and implement accommodations. I feel validated and understood for the first time in my life. I am eager to live my new start.

## My experience getting diagnosed

by **Melanie Louise**

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I was 12 years old when I got diagnosed and this article will explain my journey in getting a diagnosis. It helped open a lot of doors for me, especially at college and university, and even getting help from the Government.

It was just before the turn of the millennium and I was under the care of a psychologist at a local hospital. My parents were at their wits end, as at that point, the doctors believed autism to be in boys and that because I'm female I wasn't autistic. They just thought I was a little bit quieter than most of my peers at that age, even though the classic signs showed. Lining things up; walking on my tiptoes; serious lack of speech, with eventually needing speech therapy. Not looking people in the eyes. Not joining in with play time. No imagination. My reading was basic at best, my writing non-existent except for my name.

Whilst I was under the psychologist's care, the phrase 'Munchausen's syndrome by proxy' was thrown around [editor's note: also known as 'Fabricated or induced illness', this is a rare form of child abuse], which, understandably angered my parents, and they requested a second opinion. The nearest follow-up appointment at the time was in London. I still remember being diagnosed to this day. It was a point in my life that will always stay with me.

My parents and I travelled to London. We had a Travelodge booked for about five days in all. It wasn't a sight-seeing holiday, because for about three to four days I was being assessed. I was assessed from early morning to mid-afternoon. They assessed every aspect of me. They assessed my maths skills, my art skills, my motor skills,

hearing skills, music playing skills, people skills. Each assessment lasted about two hours. Now as a 12-year-old, this was mentally draining, with memories of it slowly fading. A few things are still clear as day though.

It was my drawing section of the assessment and it happened to be the last on the list. I followed their basic tasks, then was free to draw what I liked. I started to paint a horse, rather well, then I asked for a smaller paintbrush. This seemed to surprise the people assessing me, because it's the first time I had asked for something in the whole time I was there. I barely spoke. I would reply in one-word answers or very short answers. I wouldn't ask for drinks or food. The person assessing me asked me why I wanted a smaller paintbrush. I replied, "So I can paint some smaller wings on this Pegasus." He got quite intrigued and asked how I knew about Pegasus. Again, I replied in a short sentence, "I like fantasy and I like horses." What happened next is the reason my time being diagnosed will always stay with me.

The painting assessment was the last one on the last day. After we had finished, the people said I had done great and would I be interested in seeing their horses. Obviously I said yes. They had a driveway that lasted for miles, it was more of a hall or a mansion type building. It was a place of prestige and old money. They easily had about eight to ten horses in their fields just grazing. The horses were top of the range thoroughbred horses. The doctors I was with took me to the horses to have a pet and to feed them. I wasn't allowed to ride them, unfortunately, but just being in the presence of horses did my soul wonders.



## an article continued and a poem

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It had been an early autumn morning. It was sunny, but a cold snap in the air and frost on the ground. The typical British fog rolling in, with pristine grounds all clipped and chopped to perfection. However, it being early morning, the unfriendly hustle and bustle of noise coming from the outer grounds was starting to send me into meltdown. I could hear people's car horns, children crying on the way to school and the local people trying to get to their nine to five jobs. I was getting even more stressed, that no one seems bothered about the noises I could hear. As soon as I felt the horses, it all just swept away and then nothing but a calm feeling that still resonates with me to this day. Horses, after all, are superior beings, living in an autistic world.

Through getting diagnosed I was able to attend a school for special educational needs as students could not attend without having official diagnoses. When I had finished the special school, the help continued thanks to my ASD diagnosis. I was able to get more help at university, like qualifying for extra time in exams, having some computer equipment, such as a dictaphone to help me record classes and a special pen and a notepad that recorded my notes to a computer. I also had personal help in organising my paperwork, help with what work needed to be done and to plan

new essays; I had assistance to organise my files and keep a diary, which, in general, helped my life tremendously as it just slows my brain down that little bit more. After receiving help from the university and completing my course, I had done rather well at university. Not a full degree, but a foundation certificate.

If you are in two minds about getting diagnosed, or if you have been recently diagnosed and it has made you depressed, please seek advice on what you're entitled to, whether academically or help from the Government. I have heard too many horror stories, about bad experiences after getting diagnosed, with suicide rates slowly climbing for autistic females. These days though, there seems to be much more effort made by professionals to understand autism in women and not just us being another statistic. This gives great hope for the future, that more females get the help they truly deserve.

I have been blessed to have had a positive experience of getting a diagnosis and that's because I was rewarded with something I loved, that was close to my heart and I wouldn't change anything, in my experience of seeking extra help.

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## Neurodiverse

by **Julia**

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Verbose linguist, lost.  
Seeking diagnosis, clan.  
Refusals exclude.

Surrender not. Seek  
Deeper understanding. Join  
The dots, make more sense.

Forgive unique 'flaws'  
Re-build self-esteem. For now,  
Live marginalised.

Red tape loses us –  
Fragmentation splits, denies.  
In dark we stumble.

## Discussing imposter syndrome

by **Rhiannon**

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Please bear in mind that this article is rather subjective, what I will be discussing involves my own thoughts and experiences. I'm aware that I cannot speak on behalf of every individual. With that said, I wanted to shine a light on this topic as I feel it is worth discussing. I find it a little difficult to explain, but I will do my best!

As we know, not everyone is the same. We're not going to have the same struggles, or struggle with certain things to the same degree. We're not all going to have the same skills, or same thoughts and opinions on everything. This includes of course everyone on the autistic spectrum. I am a 22-year old university student, and I enjoy writing. I was diagnosed with Autistic Spectrum Disorder at 15. Prior to being diagnosed, I spent a lot of my child and teenhood very confused. I hardly understood myself. I was easily prone to crying, and I never truly felt like I knew how to fit in with my peers or act 'normally'. Initially, I was considered to just be 'oversensitive' due to my feminine nature, and that I would grow out of it eventually. However, it became more and more apparent as I entered my teenhood that this wouldn't be the case. Something I didn't acknowledge until after I was diagnosed, was that I had spent much of my school years learning to mask my 'unusual' behaviour. With great friends and a great mentor, I was able to keep to myself, and cope with school life. While I began to get better at coping and masking, I was only partially satisfied.

To be brutally honest, I think dealing with imposter syndrome can be very frustrating at points. In my experience, this has particularly become an issue for me in my present adult years; feeling constantly stuck in limbo. As I've discussed, I always felt out of place among neurotypical people. On the other hand, there

is this paranoia of being accused of being 'fake' or pretending to be autistic due to my struggles 'not being obvious enough' to people. As a result of my standing not being inherently "obvious" enough to some people, it can make some scenarios such as applying for jobs very frustrating. Here lies the two conflicting worries of: a) I'm independent enough that some may find my struggles over dramatic or simply not notice them, and b) The idea that some may view me as incapable of doing things. Evidently, I do find that viewing people either entirely capable or incapable is a rather black-white perception that's rather inaccurate. Instead, it's important to acknowledge the many grey areas in between. As mentioned, everyone adapts differently. Therefore, we cannot just assume every autistic person will adapt the same in any situation, eg jobs, social events, everyday life in general. For myself, I know that I am capable of most things, and I don't believe my minor struggles should prevent me from achieving my goals.

To conclude, I feel the need to point this out. I am indeed very grateful and fortunate that I can do many things independently, as I know not everyone can. With that being said, I don't believe that makes anyone better than anyone else. At the end of the day, we're all just trying to figure out life, and realistically we don't all adapt the same! No one should at all be ridiculed for having any sort of struggle. Believe it or not, society just isn't crafted to accurately fit the needs for the entire human population!

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### The rules of *the Spectrum*

(contact information for *the Spectrum* is on page 2 and again on page 20)

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## Mystery girl

by Mollie P

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When I was younger, I was known as the quiet one,  
The reclusive daydreamer who lived in her rich,  
inner world,  
I was like an enigma waiting to be cracked open;  
This meant that I was known as the mystery girl.

Perhaps I missed the class at school  
That taught the social values I still fail to grasp,  
I often feared being found out and ridiculed  
Which is why I resorted to wearing my 'mask'.

My outside-the-box thinking at school was often  
'corrected'  
So I only participated in class when I knew what to  
say,  
This is because I was tired of my ideas being rejected  
And tired of making so-called 'mistakes'.

Being 'wrong' ebbed away at my self-esteem  
It made me feel somehow defective,  
It felt strange to disagree with the mainstream  
I didn't realise that I just have a unique perspective.

This self-doubt persisted outside of class too  
As my thoughts were often shot down like  
warplanes,  
Withdrawing from conversation was something  
I got used to  
At least my mask was therefore maintained.

It is only years of self-reflection that made me realise  
Why I displayed this non-conforming  
characteristic,  
After years of masking, it therefore came as no  
surprise  
When I discovered, age 20, that I am autistic.

Society needs creativity, yet schools constantly  
hinder it  
Their end goal is to encourage mass conformity,  
Looking back, I was just a bewildered freethinker  
Rebelling at the system's rigidity.

We cannot thrive as adults when our creativity is  
impaired  
By being conditioned to hate making mistakes, or  
being wrong,  
Our educational system is falling into disrepair  
Somehow, I knew this all along.

