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# Asperger United

Asperger United is a magazine run by and for autistic adults (although some parents subscribe on behalf of their under-sixteens). The magazine aims to put people who have the condition in touch with each other and to share information so that they can lead more independent lives.

Please note that AU receives over 50 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. AU protects the identity of contributors by not printing full names unless the writer asks for his or her full name to be used.

#### Asperger United online is available at www.autism.org.uk/AUonline

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

#### Editor: the Goth

National Autistic Society production support: the Content Team

NAS phone support: the Supporter Care Team

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

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

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

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

The name *Asperger United* was chosen by the group of original readers as the most "appropriate name" for the publication. This was suggested by Anna Kaczynski, formerly Cohen.

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

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Tel: **0808 800 1050** (free from most landlines) or Tel: **020 7923 5779** (geographical charges apply) All we need is your email address and we will add you to the email notification list.

Thank you to Graeme Lawson for producing the  $\mathcal{A}U\log o$ .

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

Asperger United 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.

**Welcome** to the April edition of *Asperger United.* 

Going through the pending folder, looking for pieces to put in this quarter's magazine, I noticed that twenty contributors have, all together, submitted over a thousand unpublished pieces, which is more than half of the pending folder.

I decided to feature some of these writers, so over the coming editions you can expect to see some of the same names recurring, along with many others.

I hope you approve of this decision, and that you enjoy their writings. If you think it's a bad

decision, please let me know — contact details are at the bottom of page 2 and also at the bottom of the back page. When I know what you want, I can try to improve the magazine.

Remember, you are welcome to contact me about anything at any time: the themes that I suggest are just suggestions, to help inspire some concrete ideas in you. Whatever you choose to contact me about, I shall look forward to reading your letters and emails, which are always interesting.

Yours,

the Editor

### the enjoyable edition - suggestion for next issue on page 5

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### **Review of Locke**

#### by Kristopher

*Locke* is a 2013 drama/thriller film directed and written by Steven Knight. It is about a construction worker named Ivan Locke, played by Tom Hardy, who finds his perfectly ordered life (some might say concrete) crumbling down around him on the night before his biggest job comes to fruition. He has to deal with a woman named Bethan, voiced by Olivia Colman, who is about to give birth.

He has to deal with his wife Katrina, voiced by Ruth Wilson, who after hearing about the pregnancy does not want him back. He also has to deal with a very incompetent assistant named Donal, voiced by Andrew Scott, who is very nervous about the job going right.

Ivan Locke is a man. That is the fundamental thing about this film. He is a man just like you and me. He makes mistakes, he loves his job and he is aware that what he is doing, which is in this case going to the birth of Bethan's baby, might very well be the worst thing that he has ever done and will ever do. We all make mistakes in our life and at times we can admit it but mostly we cannot.

Locke is human enough to face up to it which admittedly does make him a bad person because he did cheat on his wife but at the same time he is redeeming himself by admitting that while he does not like Bethan, at numerous times he calls her old and at other times he calls her ugly, at least he is able to look past his hatred of her and be there for the birth of his child.

This is partly because his father, who Locke speaks to in his head, was never there for him. In other words with Locke being as flawed as he is it is easily recognised in all of us that we are able to make mistakes. I will admit that we would not be as upfront with our wives or our coworkers as he is but the time will soon come to pass when we have to admit our flaws. Locke is clearly tired of his position in life and he does want a way out of it but he is not entirely sure what that "way out" actually is.

Locke is also a rather mysterious person. Other than what we are privy to on that car journey we know next to nothing about this man. I believe that he is a person who represents the everyman type. It is a fundamental and ingrained part of our very being that we make mistakes.

We do so because if we did not make mistakes we would not learn from them. Locke represents each person who has at one point stopped and thought to themselves "wait why am I doing this?" He knows that what he is doing is going to change his life and he welcomes the change.

Admittedly getting Bethan pregnant in the first place was going to change his life for better or for worse anyway, but at least he can face up to it instead of running for the hills: as many people would, he chooses to stay. He wants to be a better person but as opposed to all of the other "better persons" out there he is actually doing something to ensure that he does not repeat the same mistakes.

Locke is also very driven by his job. In fact it is just as important if not more so than seeing Bethan's baby's birth. His job is very much like his life in that the concrete of the buildings could crumble and the foundations could collapse. Much like his own life, in fact, because as soon as he admits his transgression everything goes wrong for him.

Donal has to repeatedly ask Locke what sort of cement they are using even though he already knows. He has to get a Polish builder to repair a leak in one of the pumps and he also has to get permission from a council worker named Cassidy, voiced by Danny Webb, to close a very important road. Basically one wrong thing and the building collapses in on itself. Ironically much like the life of Locke himself it is a very fragile business.

Katrina tells Locke that he loves his job more than her. That does appear to be a statement that is not without an element of truth to it. In conversations with his family, including his sons, he seems very eager to get off the phone as soon as possible. All they talk about is a football match that is on the television.

He also says that it might be better if they do not talk to him as he is driving even though that is the point of the film, ironically. He does seem a lot livelier and more invested in the conversations involving the pouring of the cement and talking about the state of Bethan's dilation period.

In fact it is said throughout the film that this "pour job" as Locke calls it is the most important of his career. In conversations with Bethan even though he appears to not care for her (it is clear that he does care, although he does not wish to show it) he does care about the baby.

He says that the Locke family are all a bunch of losers although he wants this generation of the family to turn out right. In the conversations he has with his dead father he says that he wants to dig up the grave just to see how successful a man he has become.

Locke clearly has some deep-seated issues with his dad which he has wanted to admit for a while now. The frustration of the journey is what

If sufficient material is sent in, the theme for July will be **work**. Anything about work — employment, volunteering, things wrong with the benefits system, and anything else you think of. Vote with your contributions: the more submissions on a subject sent in (from different people) the more likely that has motivated him to do so. He even goes as far as using the worst word in the English language to describe his father.

That is why he wants to do right by the baby. It has to be stated that he cares more for the baby than for her. He tells Sister Margaret, voiced by Alice Lowe, that he does not actually know who Bethan is. That is rather fitting I think as we do not honestly know who Locke really is either. He is an enigma.

I however believe that he does care for Bethan and it is the frustration over this important job that is leading him to say all of these horrible things. Things are gloomy for Ivan Locke and he cannot do anything to stop it. It is a long car ride into the furthest reaches of his being.

It is in our nature to be fallible and flawed and to make mistakes. It is in our nature to be driven by our jobs and our thoughts. People in general make trouble and in time we do learn from it. Mistakes are an important part of our lifestyle and our genetic make-up.

Locke has flaws. Locke has made mistakes. At least he is aware of the mistakes he has made. At least he is aware that what he has done could ruin his life. Also at least he knows that he has to do the right thing. Can we honestly and truthfully say that about ourselves? I doubt very much that I could.

Tom Hardy was fantastic as Locke. He is frustrated and moody and has clearly had enough. It is a near masterpiece in minimalist filmmaking.

I give this film  $4\frac{1}{2}$  stars out of 5.

that subject will be the theme. Writing on any subject is still welcome (though I have a feeling this one will produce lots of letters) as are ideas for new themes, and artwork. Remember, if you want to see different content in AU, the best way to change it is to send something in!

# People with Asperger syndrome can verbalise their emotions with people that they know

#### by **Debbie**

It was always thought that people with Asperger syndrome could not verbalise their emotions. Email was then thought to be the natural way of communicating for people with Asperger syndrome.

Well I have discovered the root that is the cause of the communication problems.

I suddenly thought that if I could write all my feelings down on paper then why don't I verbalise them on my voice recorder on my mobile phone.

I had the shock of my life. I was communicating very effectively. I did several recordings of various issues. I practised giving differences of opinions based on the opinions that people gave to me in the past and I felt confident in doing it. I never used to give my opinions and to hear myself voice opinions felt extremely liberating. It was a different Debbie.

I then let one or two people hear my voice recordings. One was an assumption that was made about me by someone. I had wanted to tell this person that her assumption was incorrect but I didn't think I could verbalise my emotions effectively. She listened to it. My Community Psychiatric Nurse listened to the recordings and she thought that I had come over effectively.

I then rang my friend and I asked her why did I struggle to communicate my emotions face to face. She said fear. I had had another conversation with someone else and I said that I communicated face to face with my mum. That someone said that I knew my mum and she knew me. I then discovered that it was when I was with people I didn't know that I struggled to communicate face to face due to the fact that I was wary of them because I didn't know them.

Unfortunately I self-harmed because I didn't think I could verbalise my emotions. I do not want anyone with Asperger syndrome to resort to this just because they think they cannot verbalise their emotions. They can.

I did some role-play with someone and I practised verbalising my emotions effectively face to face. I was told I had done very well. I was proud of myself.

Knowing this will enable people with Asperger syndrome to form relationships and their needs and wants will be met.

What I intend to do when I first meet someone I don't know and I am entering into a relationship with them I will use my voice recorder to start with. Once I have got to know the person I will then not use the device but communicate face to face.

It will not totally eradicate all of the problems as people with Asperger syndrome may still take people the wrong way because they are literal and they may still misinterpret communication even with people they do know but a lot of the problems will go.

What we're expert in we tend to be frivolous about but what we know nothing of, we take seriously.

# Pen pals

#### Pen pal number 263

**My name is Stephen**, I am 29 years old and live in Solihull with my parents. I like football, going out for food and drink and socialising, as I have high-functioning Asperger's. I would love to hear from anyone between 20 and 35 with similar interests, who preferably lives in the West Midlands and would like to make new friends. I forgot: I also love travelling and would love to have a friend who shares the passion to explore the world. I am a regular visitor to my local gym as I like to keep fit and go swimming too.

#### Pen pal number 264

#### Hi. My name is Daniel.

I live in Yorkshire. I am 42 years old and have AS. I feel a bit disconnected so I would really like to make new friends. I love writing letters. But I can do emails.

I consider myself a friendly and caring person, and I have a lot of love to give. My hobbies are poetry and exercise. I've become a bit isolated even though I have a girlfriend. I am scared to do things without her or my parents. But by my poetry and writing I hope with all my heart to connect again.

I love watching *The Big Bang Theory* and some horror. I'm obsessed with David Bowie: my favourite album is *Low*. I love *Sound and vision*. That album has helped me through a difficult time. Thanks.

Love,

Daniel

# How to place a pen-pal advert

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

# How to reply to pen pals

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

#### \*\*Important notice — please read\*\*

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

#### Pen pal number 265

Hello my name is Natalie. I consider myself a geeky pop-cultural, fandom-type person, creative person and a bookworm. I am in my thirties (but I look young for my age) and I am from Kent (south east England). I have mild autism and I am a fan of Disney, Studio Ghibli, Pokémon, Tintin, *Family guy*, Sonic the hedgehog, *Hello kitty* plus many more (just too many to list). I also like postcards, Nineties pop music, going to comic cons, watching TV and films, going to the cinema, Japanese pop culture, listening to soundtracks including radio dramas as well and reading comic books. Would love to hear from those who are fans as well, plus pen pals who I have lost contact with.

#### Pen pal number 266

#### Hi, my name is Ozflinders.

I'm 48 years old (diagnosed with Asperger's at 42) and I live in Essex.

My interests include: listening to music, my cat, wildlife, creative writing, photography and local history, amongst other things.

As well as pen-palling I like chatting on the phone and texting my pals.

Anyone, male or female — any age — is welcome to contact me, especially if you're from the LGBT community.

## **Autistic Adult Choir**

at St-Martin's-in-the-Fields, London notice by **Brandon** 

If you like singing, have always wanted to sing but have never plucked up the courage to sing, or have always wanted to join a choir, but find the neurotypical atmosphere of most choirs off-putting, you would enjoy being part of the Autistic Adult Choir.

Since it was founded in 2015, the choir has grown to approximately twenty members. Although no previous experience of singing is needed, the confidence and ability of every member of the choir has increased greatly over the past two years or so. We sing a variety of repertoire, including Beatles' lyrics and pieces by Thomas Tallis, most of it chosen by the choir. We have already performed at a variety of venues, including the Arts Club and the Autism London Asperger Group. I have never felt overwhelming anxiety before performances. Our choirmaster, Jill Bradford, has much experience of working with people on the autistic spectrum, and always prepares the ground so well that it is an enjoyable experience for all of us. I have never felt so at

home and so accepted in any other organisation. After having had bad experiences in a neurotypical choir, I had thought that I would never sing in a choir again. I am now convinced that I was wrong.

At present, we meet for rehearsals at 6:15 pm on the second and third Tuesday of each month at one of the rehearsal rooms at the centre at St-Martin's-in-the-Fields, near Trafalgar Square. After fifteen minutes of refreshments, we start the rehearsal with exercises to warm up the voice. We then concentrate on rehearsing three or four pieces until approximately 7:40 pm.

All you need to join the choir are enthusiasm and a commitment to attend rehearsals. If you are interested, please consider joining us. We are waiting to hear from you.

Please contact us:

contact@theautisticadultchoir.com

### Asperger's syndrome: my story

#### by Stuart

At 89, I have to cope with arthritis of the legs, lack of balance (I can't walk far even with a walking stick), lack of hearing (I wear an aid in both ears). I'm slow to comprehend what is being said, forgetful, beginnings of Parkinson's. A fragile old man, who enjoyed being active in sports in his younger days, in the last stages of his life.

I can honestly say that I had never, consciously, heard of AS, until, a couple of years ago, I read an article in *The Sunday telegraph* about an actor who had recently been diagnosed as having AS, and was so relieved. Various factors outlined in the article, and more information via the Internet, were so much a match to my life that I became convinced that I too have always been a victim of the syndrome. My NHS doctor failed to concur, just accepting what I had told him and not denying it. (Of course, he only knows me as someone who seeks his advice when I have some complaint; he doesn't know me in everyday life.) There is no point, at my age, in seeking advice from an expert AS doctor.

I, too, was relieved, of course. Then my wife enumerated various aspects of my personality which she had had to put up with, such as introverted, sort of secretive, lack of communication and social skills, no small-talk, inability to read signals, facial expressions or body language. I have to acknowledge that these factors must be largely true, and I'm so grateful that my wife has chosen to stand by me. With hindsight, I'm convinced that my parents must have known that there was something not quite normal about me, but AS was unknown as such then, until relatively recently. Curiously, some friends and relations to whom I have revealed my problem had heard of it, but had no thought of it as connected with me from what they know of me, which seems to confirm that AS is not easily detected by those not familiar with it.

In my childhood, I had always seemed to be ahead of my year at school, and I gather that in my wider family was thought to be a quiet one, shy, not talking much, but clever, hoping to go to Cambridge. My continued education was damaged when war broke out in 1939, as I was at a boarding school which was commandeered by the government, and we were transferred to a hotel in the Lake District - which obviously lacked the laboratory facilities which I needed in studying science, and also the familiar teachers had been called up. So while it was a great struggle for me to carry on learning what I needed, I fortunately did just manage to get in a year at Cambridge before being drafted into war service in the Chemical Inspectorate of the Ministry of Supply for five years with little chance of keeping up with academic studies. On return to college, I chose to change to reading geography, leading to a career in town planning, in which I could have secured a top position but for lack of communication ability, which I now see as the effect of AS. I like to think that, ideally, I would have been best at something to do with mathematics.

Perhaps I can take some consolation from the reported assumption that many brilliant people in various walks of life suffered from AS?

When we're tired, our perception of our abilities and indeed the abilities themselves, slow down so that we achieve less. This is because of entropy. Without rest we cannot gather enough energy to kick start our lives, with the force to sense/achieve a lot within a little time/area.

#### Dear Madam/Sir

First, a thank you for your *Asperger United* magazine.

Second, a request to remove me from the mailing list for a paper copy, as I prefer to download each issue and reduce the amount of paper in the household, and environment.

#### Third, a letter:

#### Dear Editor

I have been learning about Asperger's syndrome since my eldest son, now 27 years old, was diagnosed by the psychiatrist some six years ago. I had not known of the existence of such a condition or rather I knew all about it in the case of my son, but not that it had been given a label. This situation was immediately complicated in the case of my son, who had developed an acute catatonic condition that we could not manage, since the psychiatrist candidly said that he could not be referred to the local hospital for his condition as it was classified as a learning difficulty, so my son was simultaneously diagnosed as suffering from bipolar disorder.

This combination of a learning difficulty with a mental health problem has been both a help and a hindrance, along with the rapid turnover of psychiatrists in the region, who have each given their own definition of his mental health problem, and variously agreed or disagreed with his having Asperger's syndrome (or even denying that ASD exists). So whilst he has been admitted to a care home on the basis of his "psychotic disorder", for which we are very grateful since he is totally not "streetwise" (in modern parlance) and needs constant supervision (he is totally gullible in the nicest but most vulnerable way), neither is he getting any specialist help, and centres dealing with ASD seem to shun him once they learn he is on medication.

You can't not like him — there is not a shred of malice in his character — and in ways I cannot comprehend, he is highly intelligent, but I am at a loss on how to help him to find friends, and so on. Any suggestions would be most welcome.

#### Dear Goth,

I hope I am not too late for the next edition, on things I enjoy.

I like to listen to the wind and rain lashing against my window pane when I'm lying in bed.

I enjoy the company of my two black cats, my boys as they are fondly known by my friends. I talk to them all the time when I'm in. This the neurotypicals find strange, when they can happily talk to a stranger. Maybe that should be neurotypical stranger.

Watching the world go by from the upstairs window of a double decker bus, on my own or occasional company of my autistic friend. Shopping in charity shops: this we share as our favourite interest.

Food is an enjoyable thing, liking some things from childhood: chocolate Swiss roll, tinned mince and mash — still favourites of mine, not forgetting the traditional Sunday roast.

A good old natter to my friends on the phone.

My jeans and hoodies I wear nothing else day in day out: it's for comfort; none of that scratchy nylony material I had to wear as a child.

The peace and quiet of my own home, with my boys of course.

Summer, sitting on the doorstep with my cats, one at each side of me. Drinking a smoothie of banana or blueberry.

Sharing the duties at church of washing up or reading from the Bible, or just having fun now the bullying has gone.

That's what I enjoy.

#### Hi Goth and $\mathcal{A}U$ readers.

My name is Daniel. I very much like to read AU. It is a fantastic read. I hope you can include this email in AU because I feel having a voice is important to me. I have lost lots of weight this year, thirty-two pounds in weight. The scales only cost me ten, so I have made a twenty-twopound profit. I have cut down a lot on alcohol and done lots of exercise on the exercise bike. I am getting fitter and healthier, with a lesser calorie intake. I am still single though and would like to meet the woman of my dreams. I have created a mission statement which could help me to achieve this, but also how to interact with people in general. It feels important for me to help people to feel loved, inspired and wanted. I really enjoy interacting with people, those minutes or hours I can do this are precious.

My mission statement is:

# MY MISSION IS TO HELP MYSELF AND OTHERS FEEL LOVED AND WANTED.

# MY MISSION IS TO ACCEPT ALL I AM AND LOVE PEOPLE THE WAY THEY ARE.

# MY MISSION IS TO INSPIRE MYSELF AND OTHERS.

This is in capital letters on my "Wall Of Confidence", which includes affirmations also. I like to read these and remind myself of my mission. I want to be the best that I can be to create as much happiness for myself and others. Hopefully in time I will become better at achieving this. The Wall Of Confidence is something recommended in a book I have been reading called *365 steps to self-confidence*. Another book I have been reading is *Overcoming worry*. This has in it a problem-solving page that I use to assess a solution's suitability. The idea is to answer the questions, but as soon as you give a no-response, try another solution instead. I love books. When I go into Waterstones I am fully equipped with OCD tendencies and feel a strong urge to buy. I transfer this compulsion to CDs and to a lesser extent DVDs.

I hope to use the problem solving technique in the *Overcoming worry* book to lessen my fears, gain a partner and greater confidence. The confidence book will hopefully help me achieve this as well. I feel things very strongly like love and passion, with the feeling twirling around and around, sometimes spiralling into depression. But my exercise and study of this confidence book has helped me to cope with heartache and longing. I do a blog on mental health. My latest blog entry is called *Sex and drugs and milk roll*. I'm not getting much sex, but at least I am on anti-depressants to help me deal with it. Milk roll is the low calorie bread I have toasted for my supper.

Love

Daniel

How do you reach through the invisible glass wall? He's so funny! A story teller! A singer! A mimic! ALL! He could be famous but if anyone exclaims so, he hides. Buries his gold deep within a hidden castle encircled by tides. How sad it makes me when some God gave him such gifts. That would make the human race in humour and fun lift. Has anyone advice on reaching through the glass wall? When there's no passageway or key to the lock at all?

## Talent, how not to train or keep it

#### by James Christie

Rifling through the pages of *The times* after a fine and fruitful meeting with my publisher at The Fox in Felpham, I found a supplement entitled *Employee engagement and benefits* and some fascinating phrases about problems facing businesses from Andrew Benett, author of *The talent mandate*:

"Amid all the alarms being raised, we hear only rarely about what may be the most fundamental crisis facing most businesses today — talent. How to get the best. What to do with it. And how to keep it."

More specifically, Mr Benett went on to say:

"The talent crisis hasn't erupted because of a shortage of workers. There are plenty of people out there looking for jobs. The problem is that we don't simply need people with specific sets of skills, workers we can slot into place as others retire. Our new, vastly more complicated organisations require high achievers with vision and drive; people who can create positions within the company that we didn't even realise we needed."

Well, much though you may want 'em, Andrew, if my experience is anything to go by, you ain't gonna get 'em.

For though I was now at the apogee of a life which read like fiction, a published author discussing the possible translation of the tales of *Dear Miss Landau* from book's pages to the tread of boards on stage. An Asperger who'd made history and crossed America for the film star he'd met on Sunset Boulevard, defined by a former fundraising officer of the National Autistic Society Scotland as "a unique human resource" and (more obscurely) a walking piece of Scottish library history, I had not reached that place (and lunch at The Fox) courtesy of the care and development of complicated organisations. Quite the opposite, in fact.

Twenty-four years ago, an organisation supposedly in search of talent found me and put me on their first-ever training course.

Fans of *The Simpsons* will know of Mr Burns and his slimy assistant, Smithers, but might be forgiven for believing (hoping?) that such creatures don't exist in real life.

Would that I could tell them they were right. I met Burns and Smithers, all right, and underneath a precipitously thin surface veneer of charm, "Burns" quickly proved himself to be (in the words of another employee) a "schizophrenic megalomaniac" and (I have absolutely no doubt) one of the one-in-twenty-five business leaders who is in fact a psychopath.

"Smithers" happily confessed that "I always do what I'm told" and he and "Burns" set out paternally to teach us the business, basically by pressuring all hell out of us in the mistaken belief this would make us "thrive under pressure."

They screamed if anything went wrong, turned the classroom into a pressure cooker, mouthed bland buzz words and despite having dimly realized they needed to find good people ("Smithers" commented early on that they were expecting lots of ideas from me), reverted to type almost as soon as they got us through the door. It really did feel like the Stanford-Prison experiment reincarnated.

At the time, I was an undiagnosed Asperger and these were unqualified teachers, acting more like sadistic old dominies from Victorian Scotland. They most certainly did not have one clue how to run a course. It was a month of living hell which I endured in the belief that this was my chance, throughout which they said they knew what we were capable of, finally admitting they didn't.

From being on the supposed fast track to the top, I was fired. You do not want to know what it felt like to go from top to bottom so fast. I think another person might have killed himself or refused to accept the experience and blanked it from his memory. With the terrible clarity of the focused Asperger (and no knowledge there was any reason for my inability to learn) I faced my failure and set out to redeem myself specifically by being published on merit. One of the hardest things in the world to do.

It took twenty-two years for me to reconstruct myself and crawl back out of the pit, during which I presented a cheery face to the world and hid the darker truth within. I once said to a friend that anyone going for a Sunday stroll through the depths of my subconscious would come back white-haired and shaking. He thought I was joking.

My course mates? They were placed in slots and did what they were told.

In the end I was indeed published on merit, but the road to that lunch with my publisher at The Fox was harder than anyone will ever know.

In fairness, I had my limitations, could never have worked full-time in the business I was supposedly "trained" for and had not then reached my maturity (I only really "peaked" at forty-four, when I wrote *Drusilla's roses*) but the ability was there and very difficult to discourage, but both that first organisation and others seemed determined to do their very best to destroy me, while at the same time proclaiming their desperate need for talent. . ..

I deeply doubt much has changed. They cannot change their controlling ways and the very people they need the most are those least likely to tolerate them!

Just the other year, I had an interview for a part-time local job. The HR man interviewing me was inflexibly set on putting me in a specific slot while I tried to suggest ideas to him he didn't know he needed.

I might as well have been speaking Martian.

In the end, feeling much like Morgan Freeman did during his last interview with the parole board in *The Shawshank redemption*, I told him to go to hell and walked out.

(Extracts quoted from *The times*, 4/3/2014)

James Christie is the author of *Dear Miss Landau*. He was diagnosed with Asperger syndrome at the age of 37 in 2002. He lives in the Scottish Borders.

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Continuing on the theme of labels, I have found that one label I even attached to myself for a long time (let alone what others attach to autistics) is "lazy".

Eventually, I started to understand that the supposed laziness has more to do with all the extra processes I need to employ just to keep up with "regular" life.

To be "normal" in other words.

That's another label that many people seem to regard more like a badge of honour, rather mystifyingly.

# AS adults with parents who have undiagnosed disorders

#### by Joe

My name is Joe and I was diagnosed with Asperger's syndrome when I was 21 years old. I believe that my father also has the condition but this is unconfirmed.

I want this article to reflect how hard it is being a son of a person with a behavioural disorder. All my life my father was never there (I lived with my mum) and it always felt like a different world whenever I went to his house. I was so used to life in a particular way that it always threw me a little whenever I came back from him.

My father is someone who had a difficult childhood himself and this was compacted when his own father hung himself soon after I was born. When he was 17 my father ran away from a psychiatric hospital at which he had been sectioned. This gives you some idea of his suffering. He went on to have five children by various women: I am the last child. He managed to build up a successful business from nothing: subsequentially became a highly respected businessman in his community. However, he never confronted his demons. This in turn affected his children. myself in particular because of my disability.

Here follow three examples of misguided parenting of which I was in receipt. One as a child of seven and two as an adult (I hasten to say there were many more of when I was a child).

In an informal mock-up play my father played the wizard and I was the helper. He had a metal spoon which he hit on his head saying it didn't hurt (he was wearing a colander as a helmet).

He then hit my head really hard (as a sort of comical effect) but in actuality was cruel. This was a memory I had blocked out until I saw it again on film. I was very shocked that this had happened to me. Many other unpleasant events occurred between the ages of 7 and 22. Years later I was trying to regain contact with him, and I was pleased when he wanted to come kayaking with me. My mother was also there as a spectator. However, the day was really hot, and I suddenly felt strange in the car.

On reflection I realise that this feeling was coming from a place of fear, as I knew he would criticise my kayaking, and it would not be a joyful experience.

I then told him I was feeling ill, and he said, "I had to re-arrange my morning to come out today". I tried to get away from him, but he tapped me on the shoulder saying, "don't you walk away I am not done with you yet". He then went to punch me with his fists, but my mother stood between us. The kayaking group of which I was a member consisted of people with varying disabilities who also unfortunately witnessed this event. This was why my father was allowed to join, because he had a mental-health issue. As it happened he went on to enjoy his afternoon kayaking; my mother and I watched instead.

Later on I tried to again build bridges. My mother and I went round to his flat for a meal. We were having a cheerful evening: I felt relaxed as it was nice to see my parents interacting, as they had never been together in the whole of my life. I reached out for a banana, and my father exploded with rage. The reason being that he vehemently objected to my taking a banana without requesting his permission first. He spoke to my mother about me as if I wasn't there in a derogatory way after having

shouted at me. My mother upped and left: I followed. I have not spoken to him since, although he has apologised. I have to care for my own mental health and this is the best way forward for me.

Thank you for reading. I have written this article in the

hope that other AS sufferers need not feel guilty about how they may have been made to feel by parents who may not have been diagnosed.

## Diabetes, Asperger's, hurt and pleasure

#### by Nicholas

Not only do I have Asperger's but I now also have type-1 diabetes which was diagnosed two years ago, which means I produce no insulin of my own any more and have to inject my own insulin so I can consume the carbohydrates in food. I do this by means of an electronic device called an insulin pump which I program.

Usually I do very well keeping control of it but life being what it is I often fail. I can have hypos — these are events that occur when the sugar which is the glucose in my blood goes too low.

I had a hypo last night: it was actually enjoyable because I have a craving for my jelly babies as a result — the jelly babies are on standby for such emergencies.

I was asleep in bed, 2:30 am, and my body wakes me up so that I can act upon my low blood sugar. I don't feel afraid, I don't have the energy, just a craving for my beloved jelly babies.

I had felt down all the previous day, feeling disheartened due to the lack of support from society for my Asperger's which has the support getting weaker over the last, I think, eight years! But now eating jelly baby after jelly baby I feel like when I've been drinking when I'm having a hypo, like when eating the jelly babies that I'm being rewarded by perhaps endorphins for feeding my need for sugar! or perhaps when having a hypo I don't have the energy to think about the things that bring me hurt every day.

Things that hurt me, like perhaps the landlord I see as being greedy — she takes more and more off me in what she calls rent and I call benefit — I pay her benefit because it certainly benefits her — she hardly does anything for it.

The government takes more and more money from me, everyone is taking, those who already have so much seem to take from those who have less.

So the hypo provided an escape and the jelly babies were my pleasure.

I don't encourage hypos but when I have a bad one it can be a good experience, not a bad one!

What we concentrate upon, we're aware of — what we disperse (move our attention) from, we lose perception of (ignore the existence of): it's not that it doesn't exist, just that for us it seems imperceptible because of our time/space relationship with it.

(It isn't there because we aren't there with it as it would be visible to us if we occupied the same continuum as it: just because your body is here, doesn't mean that your mind is focused here too.)

# An interview with an NAS-forum user, conducted by an Asperger United reader

#### by Pikachu

To Mr *the* Goth, a perhaps strange (that is, written by an autistic person) letter. And good fortune to yourself, mister, and in reading this, please sit down first, yet it is not all bad, just weird, and . . . maybe I should just stop writing this bit just now, perhaps?

Dear Mr With-Great-Respect-to-the-Mister not wearing black yet, this missive may give a take upon whether (paper) AU is "pointless" or not.

Pikachu (P): Glad tidings and good fortune to all who may read! In this letter I am attempting to write about the difference between the paper edition of AU and the online format. And we have here a first-hand witness: a user of the NAS online Community, who chooses to remain known only as DC. And so, DC, thank you for taking the time to speak to us.

DC (DC): . . .

P: Well, that is alright, I must specify my questions or answers, then, for the both of us are diagnosed with Asperger's or ASD, of course?

DC: Yes, thank you for specifying. ASD, AS, autism, OCD, PTSD, ND, NT, NAS — all of such abbreviations are commonly used within the NAS Community online forum . . .

P: Please tell us more. For example, what is the NAS Community online forum?

DC: It is a place (forum/chatroom) which can only be accessed via the Internet (on line). You have to have an email address (which I currently have) and in a way, it is like sending letters (posts) to other people (users/members) concerning a specific subject (called a thread). Just like *AU*, you can reply to others or begin your own thread. P: It sounds interesting. Do you prefer it to the paper version of AU?

DC: Not really. *AU* is on line, but I am in a unique position: I have an email address, but I can neither send nor receive. I can only post and reply to what I see. Also, there are things such as "notifications", "private messaging", "likes", "dislikes", "friending", and all types of confusing things as well. It does take a lot of getting used to . . .

P: Yes, it does sound complicated . . .

DC: AU is on line, but I cannot interact with that, because I cannot email! Also, I cannot download it. I have to read it on line, which is quite alright, but I still prefer the paper version and I always will. The NAS online Community is just that, yet at times I cannot read a post and must still print it out onto paper to read it correctly.

P: Please explain . . .

DC: Sometimes a post is very long. If it is, say, over 200 words, then that is when I prefer it upon paper. I am not alone upon this trouble, I know, from persons using everything from smartphones to laptops, and every different device shows things differently, and has differing options. That is the best thing about paper, and the great trouble with being on line, and yet the online people must often pretend that there is no trouble at all.

P:... because paper is a fixed thing and online is changeable?...

DC: Please do not get me started upon the trouble being on line has been. We are all forced

into doing it, yet this enforcement is regardless of slow Internet speed, errors, posts disappearing, spamming, malicious posts, phishing, lack of money, updates, devices not communicating . . .

P:... alright. Sorry to interrupt, but thanks so far! So it is not perfect? Yet you, DC, have a reputation within the current top one percent of the Community ...?

DC: Yes, I suppose that means about a hundred persons, given the thousands who join the NAS forum. I began in a friendly manner, yet nearly wound up being banned! Might you like to hear more about that?

P: Alright, please go on . . .

DC: I replied to a few posts, and received a genuine thank-you upon one. But then I wrote something, and the amount of hatred was astonishing at first . . . yet I wrote an apology, and said that I did not know how to use the Internet properly, and from then I found out that I was not alone. This is the best and only good thing shared between both paper and online NAS, is to find out that you are not alone, in being autistic and making errors in social etiquette. To share experiences and support other people.

P: So you went on line and found out that you were not very good at being on line . . .?

DC: I cannot refute that. It is still an education to myself, that persons feel more relaxed on line than not . . .. I do not like it, and never shall, yet it is being enforced . . . and now this is me repeating myself, is it not? . . .

P: Indeed so. One last question: apart from what you stated, how does online AU or NAS differ from the paper version of AU or NAS?

DC: A forum is like having a conversation with people whom you cannot know or see. Words must be taken at face value, for myself. Spelling mistakes and misunderstandings are common, but this is little different from real life for an ASD person such as myself. In fact, there is no difference between AU and the NAS forum with regard to content, topics, banter or tolerance . . . except that online is more instant and so mistakes and misunderstandings appear immediately. I cannot explain it more than that, and I do not claim to be an expert at it.

P: Well, thank you anyway! We may bring this to a close now, perhaps? Anything you would like to say to the readers of *AU*?

DC: Yes. The fact that AU has become mostly online never means that there are no longer any of us who still need it written upon paper. As I said, I may be in the NAS forum, but I cannot email, for I have old devices and I lack the money to buy new devices. I can understand the NAS' own disregard for such troubles, due to their need for money and their supporting children over adults (this last they do even upon the online forum). But AU existed before the NAS forum . . .

DC: Autism is a widespread matter, and to address all of it, as the NAS claims to wish to do, then the NAS needs to continue to recognise those of us who cannot use the Internet, forums, chatting, posting, emailing, friending, broadband, the latest abc devices — all of that . . .

DC: Autism is a complex affliction . . .. In the NAS' own words: "We Exist" . . . and this applies even if we cannot use the Internet!

Thus, end of letter. Thank you very much for reading,

... and concerning all of this, my Pikachu says: ... Chu-PI-Kaah!!

I certainly don't want people to think that the paper version of AU was or is "pointless", and I hope I've never said anything that allowed anyone to infer that.

That said, the interview is interesting. I received very little in response to the changes to AU, which I assume is because people were so upset at the change: please let me know what you think, and whether you print things out, Editor.

#### Dear Goth,

I wrote this for *Asperger United*: I don't know if you will publish it but I feel strongly about it. Surely there are others like this, but I do not know any and it is like being a child without any friends to play with, which feels very frustrating and lonely.

#### Adulthood – childhood

I was wondering how to say this, I feel like I have not changed since I was 10 or 12 years old and my interests and abilities are basically the same. I was watching CBBC children's television and I realised that children of that age can be very bright and intelligent but they seem very like me, although of course they are different people with different personalities. I was wondering if anyone else feels like this? I tried fitting in to the adult world at one time, but it caused major trauma as it does in children when you see they were abused or used for drug smuggling, and so on. Also, I am totally asexual and I do not feel like I understand this aspect of the adult world either and it scares me or confuses me. I feel like I have not really changed since I was 10 or 12 years old and I remember my childhood very clearly: it is like it was only last year even though it is twenty years ago.

I wonder if others have this, and if they feel frustrated by not being able to find friends who are like them? I meet Asperger's people sometimes and often they seem like adults, they have adult jobs and drink alcohol and some are married. I just want to play with my toys or go outside to run round or watch CBBC or sit in the sunshine or do a general knowledge quiz in a children's book. I get very agitated around anything that adults have to manage, like money: I cannot manage money at all and get very upset about it, for example. Also I get really upset by adult TV programmes - basically most things after 7 pm — and Radio 4 is really upsetting so we had to put a sort of ban on it in the house.

I was happy when I was a child because I was sociable with the other children I knew. I never felt stressed-out with them. But at about the age of 14 I started to get upset by all the teenage stuff going on. We always said I never was a teenager, and I think now that I was not really one inside, as well as how others saw me. I have not been able to socialise with others who were older than about 14 and I haven't made any friends in adulthood. I think this is because I get on with people until they hit around puberty and then I just don't understand them any more and they don't understand me. I really, really want some friends, but I absolutely do not live in the adult world and I wonder if anyone else is like this or has this experience. Are there others out there who like nothing better than swinging in the garden, being with family doing craft things or things with glitter like Christmas cards, playing with toys, running around, playing tig, and have no sexuality at all? My sensory system is very sensitive and I think it is this which drives my play needs, but I just want someone to play with too, so I am not alone. Does anyone else have friends to play with like this who are autistic? Or does anyone else feel the same way as I do? I really hope there are some replies; I am really wanting to find out if this is just me!

Thank you.

#### No name supplied



# The rules of Asperger United

#### (contact information for AU is on page 2 and again on page 20)

- Asperger United is funded by the NAS and readers' donations, and is independent of the NAS. Although it is called "Asperger United" it aims to be for the whole of the (reading) autism spectrum. That is, the concerns and joys of any autistic subscriber can be printed, not just Asperger's.
- 2) *Asperger United* is quarterly, published in January, April, July and October. If you do not receive a copy when you expect to, please contact *AU*.
- 3) Pieces that appear in *Asperger United* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
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- 5) The NAS would like to keep in touch with you about NAS services, support, events, campaigns and fundraising. If you want to hear from the NAS, you can opt in to this on the NAS website. The NAS will only contact you in the ways you want.
- 6) If you subscribe to the paper edition and move house, please inform *Asperger United* and include your old address as well as your new address. Even if you've paid for the Royal Mail forwarding service (or another forwarding service), you still need to inform *Asperger United* that you have moved address.
- The current edition of *Asperger United* is available at www.autism.org.uk/aspergerunited You need to scroll down to the middle of the page, where there is a link to the PDF.
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- 9) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as the line isn't very clear. Please give any phone number you leave twice for the same reason. Remember to give your postal address so that we can find your record.
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- 13) Book reviews are the most popular thing in *Asperger United*, please consider submitting one. They can be about any book, not just books about autism. Also, they do not have to be short (the Goth keeps most of his reviews short to leave more space for other writers). If you do not want your review to appear in other NAS publicity about that book, please make this clear.
- 14) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.





# Autscape: an autistic conference

Tonbridge, Kent

Tuesday, 28 August - Friday, 31 August 2018

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#### http://www.autscape.org

Email enquiries: event@autscape.org

Postal enquiries:

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- Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG Telephone: 0808 800 1050 (free from most landlines) or Telephone: 020 7923 5779 (geographical charges apply) Email: asp.utd@nas.org.uk Websites: www.autism.org.uk/aspergerunited (for subscription and the PDF version) www.autism.org.uk/AUonline (Asperger United online version)



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