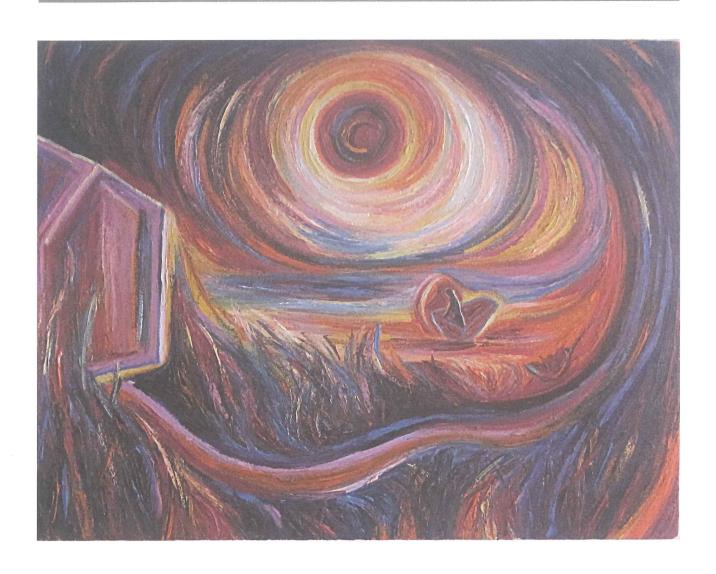
Produced by and for people who have autism-spectrum conditions

ASPERGER United

Edition 77 January 2014









Asperger United

Asperger United is a magazine run by and for adults with autism-spectrum conditions (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 200 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 is free. To subscribe you, we need your postal address. We ask for a contribution of £9 per year from overseas readers and £15 from professionals and institutions to cover postage costs. Please make cheques payable to the NAS. Organisations requiring multiple copies: no extra fee, please get in touch.

Editor the Goth

Telephone and production supportThe National Autistic Society's Publications
Department

Please send all correspondence and subscription requests to:

Asperger United c/o The National Autistic Society 393 City Road London EC1V 1NG Tel: **020 7903 3595** Fax: 020 7833 9666

Email: asp.utd@nas.org.uk

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.

All we need is your name and address and we will add you to the mailing list — free of charge.

Thank you to Graeme Lawson for producing the AU logo.

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 postal or email addresses above.

Welcome to the January edition of Asperger United.

Relationships, as ever, is a subject that produces a lot of contributions, and there are more that I would have liked to include, but space does not allow me to. Nevertheless, we have articles and letters here which show how broad this topic is, including our relationship (as a community) with the media and the general public.

One letter raises the question whether we are more likely to be gay than people in general — we have never had this debated in *AU*: perhaps now is the time.

I must admit I mention the subject with some trepidation, as whenever sexuality other than the mainstream is talked about, I get complaints. Curiously, these are either marked as not for publication or are presented to me in a way that I can't print (such as conversations, and references to other publications — printing a list of references without any explanation doesn't make interesting reading). If you do feel strongly about sexuality, please consider writing to the magazine.

As ever, I look forward to reading all your contributions, and I will hope to meet some of you at *Stim rock express*,

the Editor

the relationships edition — the next issue notice is on page 5

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Celibacy — the alternative orientation

by Colin

Hello,

I see you are planning an issue on relationships. I'm not totally comfortable about revealing that sort of personal detail, but I think my experience of not being in a relationship might be useful for some readers, so I've put together 700 words on the subject of celibacy. I imagine I'm older than most of the readers, and there may well be some young adult readers who are worried about their relationship prospects due to lack of social skills. I've tried to present singleness realistically but positively. See the attachment.

Regards,

Colin

Some people with autism just don't have the people skills to develop a relationship. This leaves us in the state called celibacy, the absence of sexual relations. A small minority of people are reckoned to be naturally uninterested in sex, but there are others who would like a relationship yet don't achieve one. My attempts to get to know a member of the opposite sex in a special way have all ended in complete failure due to my shyness and lack of social skills, and I'm pretty much resigned to accepting that it's not going to happen for me.

Celibacy has a long and mostly honourable history. In Christian thinking, the principal aim of one's life is to devote oneself to God, while marriage is about devoting oneself to one's spouse. The celibate can bypass the latter and focus their energy on the former, trying to achieve a greater depth of spirituality. St Paul commended this for those who are capable of it, either permanently or just for a short time, while recognising that most people also need a legitimate outlet for their sexual desire through

marriage. The concept of a totally celibate priesthood comes from church tradition rather than the Bible. I'm certainly in the category of being constrained into celibacy, if I'm to live in accord with the teachings of Jesus while being unable to sustain a relationship, rather than being one who makes a positive choice in that respect. This restricts any spiritual benefit it might bring me.

I do get the benefit, though, that nowadays I'm able to devote some of my time to activities on behalf of my local Asperger support group. This might not be possible if I were in a relationship and having to work to support a family. Although people with autism are often said to lack empathy, I do care about helping people to have better lives, and it's satisfying to be able to make a small contribution towards that. Also, I think the expense involved in needing a family home, and probably a car to drive them around, is frequently underestimated. I am certainly better off for not having those costs.

Where I find difficulty is not so much in lacking sexual activity, but in lacking the support of a partner. I have a lot of psychological scars from bullying, and this makes me fearful about speaking out about anything. It would help me if I could find someone with whom I could talk things through regularly; I find that just talking sometimes reduces my stress levels considerably and enables me to make progress. There are people I can go to when I'm in a crisis, but they all have other responsibilities and there isn't anyone to be just "there for me", at least that's my perception. Ideally this would be more a soul mate than a partner. But some of my thinking is so far "left field" that even this is probably an unrealistic hope.

Nevertheless my experience does at least show that it is possible to get through life without a

sexual relationship. I have found it liberating to accept that such a relationship is realistically not going to be possible. My AS diagnosis was about twelve years ago now, but, some years before, I had met someone who I was strongly attracted to. I managed to ask her out once, but she was quite clear that she didn't want to be a girlfriend. I think if I'd known then that I couldn't sustain a relationship, we would have been able to develop a good friendship. And I would have enjoyed looking at her even if I wasn't allowed to touch! But not knowing about Asperger syndrome then, I wasn't prepared at the time to settle for just a friendship. So it didn't work out, partly because I have limited interests and couldn't think of anywhere to invite her to for a second date (she wouldn't have accepted a restaurant date). I'd advise anyone in a similar situation, but with the advantage of knowing about their AS, to settle for a friendship.

If sufficient material is sent in, the theme for April will be sexuality or fandom (that could be anything from Doctor Who? to furry fandom). Vote with your contributions: the more submissions on a subject sent in (from different people), the more likely that that subject will be the theme. Writing on any subject is still welcome, as are ideas for new themes, fillers (for putting in small spaces like this) and artwork. Remember, if you want to see different content in AU, the best way to change it is to send something in!

John F Kennedy

an unfinished life

by Robert Dallek

Penguin Books
ISBN: 978 0 14101 535 4
£16.99

review by **Annette**

I was born in the 1970s. I only knew very little about him. In my library under biography I found this book. I learnt many, many facts, history of his life and the Kennedy family.

It's not a book of romance and gossip, which I was pleased about.

The discussions are serious when talking of the Bay of Pigs and the Cuban missile crisis. The Soviet-American negotiations. The civil rights troubles. The election campaigns and JFK's awkwardness. His disability and medications. His role fighting in World War II, on PT-109.

I found this book to be a wonderful historic read and

learnt about that era and the difficulties and challenges of being a president of America.

I'm glad I'm on the autism spectrum, because I have remembered with ease many topics from this book. This book also lead me to research Lee Harvey Oswald and Jack Ruby and I don't have access to FBI files. I have arrived at my own conclusion as to the assassination of JFK theory. I have an opinion that Lee Harvey Oswald acted alone and was responsible for shooting JFK.

Author Robert Dallek's writing style made me feel I was part of those boardroom meetings, and I'm glad I wasn't there. An enjoyable book to understand and learn this period of history.

This book and the one on page 13 are available from all good bookshops and through Amazon's charitable scheme at www.autism.org.uk/amazon and if you use this address instead of the usual Amazon one, the NAS gets a donation from Amazon.

Dear Sir / Madam,

we have been members over twelve months now and, ironically, in the first edition we receive, you review the book *Asperger syndrome and long-term relationships*. As an NT partner to an AS man diagnosed at 59 years, this book has been invaluable to us both — but especially to me. It has helped me understand many "situations" and us to move forward.

Yours truly,

Susan

Dear AU

In reply to Tom's letter (Postman from Hell) October 2013 issue.

I feel that Tom making a complaint about the postman was the wrong way to go about the situation, as this has only made it worse. The way I see it from my point of view is that this postman hasn't done or said anything unpleasant to him. Because maybe Tom is new in the area, maybe the postman doesn't know him very well, so may not know what to say to him. Some people who are neurotypicals sometimes find chatting to people they don't know hard and don't know what to say to them, just like us Autistics. Okay, maybe the postman is rude, and obviously Tom complaining about him has made it worse. I suggest you ask your social worker or support worker if you have one, or maybe a family member, to get in touch with the Post Office and explain your disability, the affects it has on social interaction. If the postman is aware of your situation he might make allowances for you.

Goth,

I'd like to respond to Tom who is having trouble with his postman. Whether or not you print this please tell Tom that:

- 1. The Post Office have mishandled his complaint. It was unprofessional of them to inform his postman that he had made a complaint as it made it possible for the postman to challenge Tom about the complaint. A conversation which could be seen as the postman being rude to Tom yet again or even threatening him. What the Post Office should have done was raise the issue with the postman without disclosing Tom's identity, and then contact Tom to ask him if matters had been resolved to his satisfaction.
- 2. Tom now needs to complain to the Post Office about their mishandling of the complaint. Tom needs to ask the Post Office to address the fact that he has been left being served by a postman who has a track record of rudeness towards him, which has not improved even though Tom made a complaint. It might be worth Tom pointing out to the Post Office that he has a communication disability and is vulnerable.

I would also like to say to Tom that he can be assured that he has been reasonable in his actions: he was polite to the postman, he did nothing ill considered but judged the postman's behaviour by watching how the postman behaved with others, he offered a solution which would have avoided the need for the postman to have unwanted interaction with him, and lastly he has stood up for himself. Well done Tom. You have defended yourself with dignity.

Best wishes

Caroline

Siobhan

In a sense, I think both Siobhan and Caroline are right. Tom would have been better off dealing with the postman informally, with help from someone with good social skills, as Siobhan says — the situation can still be rescued this way. A formal complaint is a last resort, but if you are determined to pursue a formal complaint,

Caroline describes what to do. It is possible that the Post Office reacted to the complaint in the way they did because someone at the Post Office felt the complaint was over-thetop or malicious. Others often read typical motives into our non-typical behaviour — follow Siobhan's advice and let them know your real motives, Editor.

Pen pals

Pen pal number 166

Hello there! My name is Chris, I'm 16 and currently hailing you from Weston-super-Mare!

So, where to begin? I'm a (young) man of simultaneously many and few interests! PC gaming has to take the top spot, as it's what I spend the majority of my time doing. I enjoy music very much, although I do not favour any genre or composer. I am also very fond of the dexterity arts, especially contact juggling.

Some of my more fleeting interests include archery, fencing, lock picking (legally!), poi, staff spinning and many more! I am a jack-of-all-trades and master of none, to say the least!

You see, many of my interests are fleeting because I have an attention span equivalent to a ferret with a shiny thing. Once my attention is focused, I'm not moving, but give me another slightly more shiny thing and I'll cling to it like my life depends on it!

Which flows nicely into my second point.

I consider myself a furry (part of the furry fandom), and am hoping to find out if anyone shares this interest. For all you hyoomans (I use the term ironically, of course, I'm not that pretentious) Google is you friend. Perhaps you may find you share the interest (just make sure you get the right information, we tend to get a bad rap). I don't really interact with the community much, but I'm still interested in talking to some other furs.

I feel this is getting a tad too long now, so please, furry or no, don't be afraid to get in touch! I'll be checking my mail! Goodbye!

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 given 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*.

How to reply to pen pals

- Please remember to let us know the name and number of the person whom your letter is for. (All pen pals are numbered by the editor, not the person who sends in the advert.)
- > Please remember to put your address on your letter.
- > To contact a pen pal, please send your letter to 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.

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

Pen pal number 167

Hello, my name is Sarah. I am 31 years of age, I was diagnosed with Asperger's syndrome in 2010, plus I also have a hand and eye co-ordination learning disabilty called dyspraxia, and I also struggle with the dyslexic side of things. I live in Manchester. I am a very happy and outgoing young woman, I have a very close family, and a Jack Russell called Patch and she is four. She is my life to me, however I only have a small circle of close friends that really understand me and with whom I socialise on a regular basis.

I am also an auntie which I love, having such fabulous nieces and nephews that love me and look after me, and I love spending time with them all. I live independently in my own flat, as I am very independent young woman and I like to be able to make my own choices and decisions.

My hobbies are to spend time with my family, my nieces and nephews. I also enjoy to go shopping, and going to the cinema and the theatre, as I like to see my stage shows. I also enjoy concerts. I also enjoy my days out to theme parks and to different places of historical interest. I like to read and to go swimming, plus, I enjoy nights out with my friends to karaoke bars and I love karaoke and I like to listen to my 60s, 70s, 80s and 90s music, right up to today's music, as my parents were in the forces and they brought me up to listen to all sorts of music. I also enjoy listening and going to brass-band concerts, as I go in memory of my late father as he loved his brass bands.

I would also like to mention that I have a hobby which is not to everyone's liking, as I am a member of a paranormal group, but this hobby is quite interesting as we go to lots of different venues and we conduct our investigations overnight. I love being a part of this group as it is run by my best friend and her husband and she is also a spiritual medium.

I would like to be contacted by other young people who are like myself with Asperger's syndrome who would like to get to know me and who are around my age, thankyou for taking the time to read my ad and I hope to hear from you very soon, take care, x

Pen pal number 168

Hello, my name is Alain. I am 20 years old and was diagnosed with Asperger's syndrome when I was 3. I am socially active and am noticed as helpful by others. I live in Kent.

I'm mainly into cartoon shows like *Pokemon, Digimon, Yu-Gi-Oh* but I'm mainly into Transformers. For computer games, I'm into *Transformers, Call of duty, Guitar Hero/Rock Band* and *Gran Turismo 5*. I have five cats at home too.

For sports I love table tennis. I play it three times a week and on one of them days I play in a league. I also go swimming when I can and I go karting when it's warmer and the weather is nice.

I have a very wild imagination and am very creative and so I spend some of my free time during the night doing story writing in which I hope I can eventually publish.

I would like to be connected to someone through Pen Pals who has similar interests with me and also lives reasonably near to me as I would like to be able to write to the person first and then meet them properly once we get to know each other a bit more. If possible I would prefer a female as with the emotional problems I have I would like to be able to speak to a female person as I don't really exactly have a female person to talk to about things that I'd rather keep my parents from worrying about too much. I would like the person to be roughly my age from around 18-22. It doesn't have to be someone that fits all of this but I would prefer it if it's possible. I thank you for reading my advert and I hope to speak to you soon.

It is recognised, is it not, by some authorities that, pro rata, there are a greater proportion of gays — male and female — amongst those with autism and Asperger's traits, than there are amongst neurotypicals in the neurotypical world. This has been mentioned in passing by such experts in the study of autism and Asperger's as Tony Attwood and Donna Williams (qv. their publications). And yet, still, there is no provision made, nationally, for a contact phone number or address for gay auties and Aspies seeking help in managing their lives. This would be deemed an essential, surely, seeing the problems auties and Aspies have in socialising, and the further problems most of them have with the psychological baggage they have also inherited viz anxiety conditions, for just one instance.

Maybe the LGBT National Helpline should be informed of this anomaly (020 7837 7324, LGBT is lesbian, gay, bisexual, transgender) and, with help of the NAS, try to cover this need. Maybe — yes — auties and Aspies will need to do this work of providing a contact help line? Maybe such a number could be advertised in Gay Times? But, with autie and Aspie difficulties with perception, sometimes meaning-deaf, maybe it's best just to have a text number, or an e-mail address This latter also so including those who can only maintain communication by typing. Again, maybe local or county LGBT contact or help lines should have the matter put to them, so that they could consider providing outreach to lone gay auties and Aspies?

Whatever may or may not transpire in giving this some thought, here it's thought by some that maybe Asperger United should consider providing some little material to show that gay Aspies are not out there on their own. Yes.... Just think of it, there you may be, a gay Aspie, and don't realise that there are some few like yourself there reading each issue of Asperger United, you, like them, possibly locked into you own lonely world.

Warming upon the theme here, can it be said that during the 1970s there was for some years a national movement or social organisation for gays — CHE (Campaign for Homosexual

Equality) — which provided a social scene for gays nationwide at all main centres? This is now defunct, a remnant of it but remaining in Gaywest in Bristol and Bath. This provided an outgoing healthy social meeting point for gays, it providing meetings in members' homes, trips out and about (picnics, rambling, cinema, theatre), and, indeed, in one enterprise by the Cornwall branch organised a weekend at a guest house (less of a challenge than the Edward Carpenter holidays) Can one imagine here the freedom and camaraderie? Like the autie and Aspie meetings you may currently attend, except transposed to a meeting of gays!? Think of the freedom of thought, talk and expression, and the company, that company, like yourself, recognising and allowing for each their problems Yes Can we even dare follow the thoughts here to such a conclusion as to even have that nationwide programme of gatherings?

I suppose gay organisations in the Bristol area would be most amenable to suggestions put to them upon what has here, in total, been outlined There is the contact there for disabled gays anyway, and Gaywest, as said, is a remnant of the great CHE socialising organisation. . . . London, however, is, for now, an unknown quantity to the writer of this piece. As for group get-togethers, there are the four rather unique Vision hotels (run by the Action for Blind Persons), experience of which has shown the great atmosphere, company and friendship found there, the management geared to help for the disabled and disadvantaged. They are found in Bognor Regis, Teignmouth, Weston-super-Mare and the Lake District.

A phone number — for text messages only — and an e-mail address has here been left with Asperger United for them to use their discretion in giving it should anyone wish to make contact or discuss the contents of this piece by contacting Asperger United,

Geoff

AU often prints letters from gay writers, because it often receives them. If you want to see more, please write an article or letter for publication, Editor.

Hi there.

I know that this letter is probably too late to be included in the January 2014 issue of *Asperger United* but I thought I'd send it in anyway.

I have been lucky enough to have one central relationship in my life that has provided all of the social stability I have required.

I met my best friend/ partner, Sam, when we were both 11 years old. From the first day there was a spark between us, one that meant that when I couldn't find the answer to a social problem or situation Sam was always there to help me.

Despite problems with our families (mine have never accepted that I have autism or any other mental problem and Sam's weren't impressed with the new, odd, friend!), nothing has ever come between Sam and myself. It was Sam who first dragged me to see a doctor about my mental health issues, resulting in my being written off sick for two years before being listed as permanently disabled and unable to work.

Sam has always been ready to both stand between myself and the rest of the world and also to act as my interpreter. Sam has patiently explained what expectations every different social scenario will bring

and has carried my excuses when, at the last minute, my courage has faltered. For almost as long as we have known each other Sam has assured me that my misunderstandings come about because I am "hardwired" slightly differently to the majority of the populace around me.

Our relationship has survived through thick and thin: bereavements, job losses, disabilities, operations and more. Despite the fact that I live in a world quite different to the one Sam inhabits (Sam's is far more outgoing than me!) we have managed to find a way to express our feelings that works for us. When I say "I love you" I may not mean exactly what Sam does, but I can be confident that Sam knows what I mean and that it is enough.

I can say without doubt that it is Sam's faith and love that have kept me going since we met and it is almost entirely due to Sam's hard work that I have recently been officially diagnosed as having Asperger's syndrome, at the age of 44. As a psychology graduate, to Master's level, Sam had studied the autism spectrum of disorders over several months. Some further research on the internet convinced us that this was the definition of my "hard-wiring" difference and then began the long process of convincing the various doctors to whom I have been referred.

I know that I have been lucky — much luckier than

many of my fellow sufferers — and so I would like to take this opportunity to say

I love you, Sam, and I thank you from the bottom of my soul for loving me back.

Regards

Bethanie

Dear AU,

I saw the next edition was on relationships and although I have never written to $\mathcal{A}U$ before, I felt it may help me and others.

I have AS, ADHD and mental-health problems (I am currently detained under the Mental Health Act) and relationships are something I really struggle with. I either go nowhere near people or I get unhealthily attached — which has caused major issues including me getting arrested.

I hate that I am like this but seem unable to change.

I was wondering if I am alone in this?

If not, I would love to hear from anyone who has any advice or just simply understands. Please reply through AU.

Thank you,

Alex

My view of autism

(written as if by a young boy with Asperger's)

by **Andrew**

My autism makes me do things and I don't understand why.

I sometimes hurt other children and sometimes make them cry.

I don't always understand the words you say with the sounds of the lights buzzing round my

brain. . . . The tiny noises you can't hear I hear again and again!

I need the rules to be followed and I don't like it when they're not.

I forget I'm not an adult and I tell you off . . . a lot!

Sometimes when you come near me I think you are invading my space.

I may have an extreme reaction because I feel you're in my face!

I like to be first at everything and may push you in the queue.

I do not mean to be rude, it's just something that I do.

I like to be the leader and take control of how we play.

I may get cross when I find that you will not play my way.

I don't like getting into trouble and I want to be your friend.

The unkind things I sometimes do are because my brain won't mend.

You may see me spin, hand flapping and body shaking till I go red.

It's just my way of coping with the lack of balance in my head.

I get fixated on a topic and will speak of it all day.

I do not mean to bore you but it's important to me to say.

So next time you see a meltdown, don't look and laugh and stare.

The child is not always naughty. Please be autism aware . . . \boldsymbol{X}

Beware the Asperger snob

by **Edward**

I suffer from Asperger's syndrome — but I am not an "Aspie".

"Aspies" are often narcissists, preening themselves on the distorted and superficial public perception of autistic people as quirky but endearing geniuses. They wallow in a perverse celebrity, conferred by fascination with novelty.

I listened recently to a grotesque representative of this emerging breed on a Radio 4 programme. "You see, you are what is called 'neurotypical'," he patronisingly explained — whilst simultaneously elevating his own cerebral status. "My brain is wired differently from yours," he boasted. "We think differently from you."

The National Autistic Society aims to banish indifference to the needs of those with autism-spectrum disorders. But some self-styled "Aspies" threaten to diminish the full significance of these diagnoses in the public consciousness.

A parallel phenomenon can be drawn with changing attitudes to obsessive-compulsive disorder (OCD), which has captured a taste for exotic freakism while at the same time — and as part of the same process — trivialising the nature of this mental illness. The tabloid press "revealed" that David Beckham's liking for lining up his beer cans in the fridge was "evidence" of OCD, for example.

Shortly after this "revelation", a television programme showed a panel of "experts" diagnose OCD in an individual solely on the basis of his seeming dislike of having to muck out a cowshed.

It is now not uncommon to hear people describe themselves as "a bit OCD". Where once we used words such as fussy, pernickety, fastidious or perfectionist, now there exists a

growing tendency to self-diagnose, acquiring pick-'n'-mix mental illnesses and goody-bag personality disorders.

Accepting, understanding and making something positive of our differences is to be encouraged and applauded. But celebrating deficiencies and disabilities is absurd, perverse and distasteful.

Asperger's makes life difficult. It is a condition in which I find no cause for celebration. I was in primary school when my parents and family doctor turned to a psychiatrist for help in understanding my disturbing behaviour. Half a century later I was diagnosed with Asperger's and OCD. Too late, of course, to mend those broken relationships, claim mitigating circumstances in the magistrate's court or to put the career ambitions back on track. All that damage is irreparable. But, at least now, I have gained some insight into my difficulties.

Wanting to learn more and understand this condition, I wondered how other people had found ways of living with it. Books, articles and the NAS — and, of course, *Asperger United* — have all proved valuable sources.

TV and radio, unfortunately, tend to offer only brief, superficial discussions. However, I have discovered through reading sincere, troubled, wise and courageous individuals forging a meaningful life in spite of their difficulties. Unfortunately, I have also discovered the "happy Aspie", a self-aggrandising sub-group of individuals, celebrating and trivialising the condition from which I and so many others have suffered for so long.

Blinded by the light of their imagined celebrity, these naïve stars-of-syndrome are dumbing public understanding and numbing public sensitivity to what is a serious and disabling condition.

Asperger's is — like OCD and ADHD — becoming fashionable. Increasing numbers of "happy Aspies" parade their illusory charms before an ignorant public; flaunting their oddity for which today's prurient, freak-hungry media will offer fifteen minutes of fame.

But, when the curiosity of the audience has been satisfied, attention will be redirected toward the next freak on the block. Asperger's will no longer excite the public imagination.

The legacy of the "happy Aspie" will be a society which has "done" Asperger's; printed the t-shirts; worn the badges — and moved on.

And after all, why should anyone care? These happy Aspies don't seem to. On the contrary, their smug self-satisfaction suggests they wouldn't have things otherwise.

By promoting Asperger's as the latest must-have, "happy Aspie" is re-sowing those seeds of indifference, undermining the raison d'être of the NAS.

Of course, even people with Asperger's are entitled to be happy. But if you are happy because you have Asperger's, then maybe you don't.

Please remember that the views expressed are the opinions of the author. If you disagree (or agree) please consider contacting AU, Editor.

Meditation for Aspies

everyday techniques to help people with Asperger syndrome take control and improve their lives

by Ulrike Domenika Bolls

Jessica Kingsley Publishers ISBN: 978 1 84905 386 0 £12.99 / \$19.95

review by the Goth

A lot of people are put off just by the thought of meditating. Some people are afraid of the effects meditating will have, others assume that you have to be religious to meditate, and others don't understand what the benefits are and so aren't motivated to start. This book addresses all of these misunderstandings, along with others, and is clearly broken down into sections, including how to motivate yourself, what to expect, what to wear, and how to choose the type of meditation that is suited to you. And all without have to believe anything about god.

The author rejects any need to link meditation with religion, even if you are religious: the book

is completely secular in its approach, and in its advice to the reader about why a certain type of meditation may suit you.

She is also clearly a lover of film, and the book is peppered with references to mind-bending films like *The adjustment bureau*, *The matrix* and *Being John Malkovich*.

Ultimately, it is up to you whether you try meditating. Just remember that many people, including the Goth, use it to manage their anxiety, panic, and repetitive and intrusive thoughts. Some types of meditation are great for settling your mind for sleep, too.

Relationships

by Ruth, "The autiste formerly known as Genyin"

Glossary: xe and xyr are gender neutral pronouns used so as to encompass and include people who don't fit into the usual categories of him/her, he/she, his/her...

Human beings are said to be social animals. We need other people in our lives and rare is the kind of person who can happily live for long periods of time without human contact.

Autistics, on the other hand, are stereotyped as loners, not needing or wanting other people around. Our difficulties with eye contact and lack of expressed body language serve to confirm this stereotype to the uninformed.

And, often, we are on our own much of the time, even those of us labeled as "able" or "high-functioning". We appear to fail to join in, and if we try we may find it impossible to discover common ground, even with other people on the spectrum.

So does this mean we really are loners, wanting to shut out human contact? All evidence I've seen says a big NO to this. Far from being loners, most of us are lonely. Others, forced into inappropriate (for them) situations with other people are overwhelmed socially.

How then does an autistic adult find the appropriate level of social contact, and people to accept xyr as xe is?

I'm 34 years old. Currently the person I spend most time with is my landlady. Aside from her I have one potential local friend. That's a pretty limited social circle. I also have a small number of special people in my life — people who live a fair distance from me and who I see infrequently, but who have genuine respect for me as an autistic person. Most of them have something to do with autism. One has a HFA

son; a couple I know are likely both undiagnosed Aspies, and another used to teach yoga to people with disabilities. Another friend has a personality disorder diagnosis but identifies with a lot of autistic experience (though she accepts the PD diagnosis as valid for her). My friendship with my cousin is based on high mutual respect for each other as people who have had difficult lives and yet still work to make the world a better place.

I think what has happened for me is that I've sifted (and been sifted from by others) the people I've met in various situations — the psych hospital, a Buddhist centre I lived at, an autism support group I attended, etc. I've found a small number of outsiders, most of whom are passing as mainstreamers . . . and they have found me. I'm verbally intelligent and my humour attracts some of these people. Others have a genuine respect for my life experience and I respect their struggles and how they have found accepting corners of the universe.

To find unusual people one may well have to look for unusual situations. About half my unusual friends are Buddhist. I met mainstream outsiders when I briefly took up bellringing. Botanic gardens will often have such people on their workforce or as volunteers.

Another place to find them is among disability and care workers. My wonderful landlady worked for Mental Health Media. My ex-yoga-teacher friend taught classes for people with mental-health problems. I knew an exsupport worker (who sadly died) for quite a while after he left his job.

Some people on the spectrum now find friends through local support groups for autistic or Asperger's adults. This didn't work for me. I felt like an alien even among other aliens! I felt my issues were not very similar to others

in the group. I knew more about ASDs, and disability issues generally, than any of them, and was surprised by their lack of interest. It made me aware of the dangers of thinking that my place in the world might be with others who have a similar diagnosis. My place seems to be with other mainstream outsiders, diagnosed/diagnosable or not.

In terms of daily or weekly social contact needs, I find these difficult/impossible to meet satisfactorily. I work in a charity shop in the next town two or three half-days a week, and I see my landlady mornings and evenings, so I'm less lonely than I have been in the past. I am on a number of e-mail lists for autistic adults and am fairly well known in online autistic community, which helps a lot, as does being an organizer of and attending Autscape (www.Autscape.org). I am recognised by a good number of local people when I'm out and about, though faceblindness means I'm often unsure who I'm smiling back at!

I guess I have just barely enough successful social contact to stop me feeling worthless and pointless, though not enough to stop me lamenting my inadequacy at times. I'm trying

to come to terms with this as "the nature of the beast". I don't want to not be autistic — I wouldn't be me, with my interesting history and fascinations — so I must accept the downsides too.

I have some fascinating people in my life, if at a distance, and I've had a fascinating life so far. Relationships, in my unique brand of ASD, have been both a blessing and a cause for anguish. This, along with other ASD related characteristics and events in my life, gives me a real chance to develop my spirituality through practices of graciousness, acceptance and transcending habitual/instinctual reactions. "Life is hard and then you die", but it's what you make of it and yourself along the way that counts.

I have asked that "person first" language (eg., "people with autism" rather than "autistic people") not be used in my essay — all of an autistic person's experience and understanding is informed by their autism as well as other factors, thus the personhood of the autistic person is not separable from their autism.

Cover art

Nicola Wills is a London-based abstract artist and produces work both in oils and pastels. Her art focuses very strongly on the vibrant, expressive use of colour and consists of representative imagery which range from abstract to figurative. She is particularly concerned with the visual interpretation of sound and as a keen listener of a wide variety of music, she is influenced by many pieces which evoke specific shapes and colours in her mind. She uses her own emotional responses to music as a source of inspiration for the colour and spontaneous line flow which is a major feature throughout her work.

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Glimpses of normality

Glimpses of normality
Hit and scatter clinquant
A brief enlightenment
Flames slight seconds in the retina
Burns in a meaningless spectrum
I am blind to the rapport of men
That common man who inherited
The architecture of love and Chaos
Leaving me but with glimpses of
Normality, that explode and tempt
My longiness to be forever in that glaring
Certainity. Through the darkness of the day
I dream of my own Damascus.

Relationships

by Robert

aspyscot@live.com

Rob asked for his e-mail address to be printed so that, if you have computer access, you can contact him about this letter if you want to. Please consider writing to or emailing AU as well, Editor.

What a cornucopia of subjects in issue number 76. The intended subject of next issue is relationships so here are my thoughts.

As in all things, those of us on the spectrum must take heart in the fact that the problems we find in our attempts at relationships (whether friendships, parental, spousal or sexual) are common to NTs as well. Due to our "different wiring" our responses are in some cases much more intense and conversely sometimes we fail to react.

Now here I must mention our nemesis "empathy": much has been said about this already but it does colour all our interaction with NTs. My personal opinion is that empathy is a learned emotive response system, learned in infancy using "mirror neurons" (either we don't have them, or they don't work in our infancy). Research now shows they develop/switch on in us in later adulthood (great lads, we can talk to girls just when we are old enough to be their grandfathers).

Now, in relationships with NTs (which is all I can communicate about personally) we have to realise how frightening we are to them: let me explain this. Imagine you go to look in the mirror and all you see is your outer silhouette, no features. That is what some NTs see when they look at us: the picture is incomplete because the empathetic responses are missing, this can be disconcerting and sometimes frightening for them. So like Tom with his demon postman, you can suddenly have someone who seems to hate you, simply because you frighten them internally: in males this response can be aggravated by their "manliness".

It is well documented that individuals on the spectrum have trouble with social interaction, blamed on lack of empathy, but as many people have written here, some of us have some or all of the emotional responses, it's just that we don't use a subconscious reception level to instigate our responses. So we have to use our highly tuned observational abilities (believe me, NTs don't notice most of the world around them) and then learn the appropriate response to gain what you require. So you can learn to respond to NTs in a way that makes them comfortable if you wish, but remember this is hard work and would it lead to a real friendship? Personally I chose not to have friends, but back then I was not diagnosed and I basically believed I was weird. These techniques can allow us to instigate possible friendships of a shallow nature, but eventually you have to explain you gifts and difficulties. Obviously reading this means you know your position on the spectrum so you can choose your moment to explain them: in a way this can test the depth of the friendship, but be prepared for disaster.

Throughout my life I have developed an "act" to be "normal", which has allowed me to interact with people, but this negates the possibility of friendship due to the fact it's not the real me. Something I find intriguing nowadays is that with the higher profile of Asperger's etc. on TV in particular, young people are beginning to realise the depth of friendship they can experience with people on the spectrum, so yes, the imagery is stereotypical, vacuous and condescending but it has one good point. I spoke to a young boy recently who realised that his best friend was on the spectrum. During our conversation he realised this lad would probably die for him: his

tears (still confusing to me) I assumed to show his depth of feelings.

Now for love: I believe that we fall in love exactly the same as NTs, just more intensely, because with us it's a conscious choice, not an emotive response. The problem here is we may fall in love many times but not even be able to speak to or about him/her/it. This is true for NTs also but somehow they can move on easier than us — again I think this is due to the depth of feeling we have in our consciously controlled minds. So on into a relationship with an NT, I have to say it's rough, they are so hard to understand. Really I shouldn't be writing this bit because I'm so bad at it. Anyway the friendship techniques might get you close enough to the object of your lust/affection: now what? Well the advice of a failure would be, it's the same as for NTs: communication. Yes, something is painfully obvious to you but if the "normal" one doesn't see it you will have to explain. Not in infinite detail or as a lecture though (I still have trouble with that one). You have to be painfully open about your difficulties — remember they don't understand how a gap in a supermarket shelf can send you into a state of complete panic — and about your gifts — they won't notice the infinitesimal details the way way we do. A personal observation is that NTs require constant verbal and physical re-affirmation, ie., constantly telling them you love them even though you

should only have to say something once if you mean it, and hugging — they love hugs even if it causes you pain or nausea; hugging seems to be a prerequisite. These are of course personal observations, of which I have many, and I hope to share and indeed contest them.

As in Michael's analogy to Maltesers (ummmm, chocolate), we do not belong in a box, but we are in a category, which can define our possibilities. Yes we are individuals, refreshing in our differences, but we share a common gift in that our brains are better-wired than the masses, we just have to learn to cope in the so-called normality that the demographic majority favours at this time. So if you choose to bond with an NT remember they can be cute and even cuddly but they are unpredictable and can bite: if you cannot detect the humour in this statement you have a lot of work to do.

I know that there are many more difficulties for us than I mention here: rigid routines, stimming, etc.

And there are many more problems with how we are perceived by the NTs we interact with but I think that if you really want to undertake relationships there are enabling techniques. I have no idea how relationships between people on the spectrum develop and continue: I would be very interested to hear from any such people.

Passport to individual autism support

designed by Cos Michael

notice written by the Goth

Included with this edition of Asperger United is a leaflet, the Passport to individual autism support, or "autism passport" for short.

It was designed by Cos with the help of dozens of people on the autism spectrum and includes all the most common effects of autism. It is designed to be filled out to show your particular difficulties and needs, so that in situations like the doctor's or when you are very stressed you can hand it over rather than trying to explain.

Please let me know if you find it useful.

Dear Asperger United,

I picked up the July editon at the NAS, and would like to respond to Sue on page ten.

I have to say the behaviour of the woman toward Sue at this church was not Christian. John, ch. 13 vs 34-5, helps to identify true Christians. Bullying is something I suffered from at secondary school, so I fully understand Sue's reaction. Though you got expelled, that pastor was also acting in an unchristian way (ie., it was easier to get rid of you politely rather than counsel the bully on her behaviour). He obviously did you a favour as your health is much better and you have had no meltdowns since then. I've had these, they are horrible and leave you totally spent both emotionally and physically. As for that old man who shouted across the room at you about being in mental-health work for thirty years, he displayed darnel-weed-like qualities (see Matthew, ch. 13 vs 24-30 and 36-43).

I don't know the reason for attending that church. If it was for social reasons, maybe a social club for those on the autism spectrum (and maybe other disabilities) would suit your needs — they will understand you and accept you for who you are. If it was to try to serve God, then

Acts, ch. 15 v. 14 will point you towards those truly serving Him. I have been fully accepted for who I am (I have HFA and dyslexia) by all those in my congregation, and by all those who visit on holiday, too. During the two weeks I was in the UK, I attended a church in Bishop's Stortford: none of the congregation had I ever seen before. I was welcomed and got to know them.

Lastly, another thing I discern from most of the letters is, "how can you fit in with the NT world?" Please don't forget it is your world too and you have just as much right to life as they do. If one finds "why" evokes a negative response it's quite easy to say, "that sounds interesting, could you explain that more fully, please?" You have shown an interest in that person and this should elicit a more positive response. We all need to get on with each other, so the onus is *not* all on autistics to conform. NTs need to *adjust* to the needs of others too, particularly towards those less able than themselves in whatever way that may be (not just autism). We need to support each other. I hope I have done this,

with thanks,

Rhett

When she goes

by **Daniel**

I like the mistletoe
The rush of adrenalin when she goes
With the moment
With a kiss
One of these and my heart skips
I reach for the stars
They twinkle in her eyes
And I will spend Christmas
This year in paradise



The rules of Asperger United

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

- 1) 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 subscriber on the spectrum can be printed, not just Asperger's.
- 2) Asperger United is free and 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.
- 4) Asperger United administers the copyright of everything that appears and it does this on behalf of the authors.
- 5) Asperger United does not use your contact details for anything other than administering AU. Your details are not passed on to NAS Marketing, NAS Fundraising or any other organisation without your written permission. Please consider getting involved with the NAS campaigns and events.
- 6) If you move house, please inform *Asperger United* and include your old address as well as your new address.
- 7) Even if you've paid for the Royal Mail forwarding service (or another forwarding service if you live outside Great Britain and Northern Ireland), you still need to inform Asperger United that you have moved address.
- 8) 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.

- 9) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 10) 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.
- 11) You can sign up for an email notifying you whenever a new edition of Asperger United is posted on the webpage above. Email asp.utd@nas.org.uk asking for the notification by email and please include your full name, postcode and let us know whether you want the paper edition too.
- 12) If you want to unsubscribe from the paper version, inform *Asperger United* and include your postal address. Or to unsubscribe from the email notification, include your email address.
- 13) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address (for the paper version) or email address (for the email notification).
- 14) 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 the NAS section of the Amazon website, please make this clear.
- 15) 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.

Asperger United



Stim rock express - the show

or

Stim Rock Express presents . . .

A new variety show produced and performed by adults on the autism spectrum is coming to London soon! The show is an amateur production which will feature comedy, music and other performing arts.

Date: Wednesday 23rd April 2014

Time: **evening**, exact time to be confirmed (see website for details)

Location: **Tea House Theatre** 139 Vauxhall Walk London

SE11 5HL

Price: £5 (all profit generated from ticket sales will go towards funding future Stim Rock Express productions).

Booking is not essential but highly recommended (our last show was sold out). If you would like to book a seat, please send an email and you will be sent further instructions, or call or write (details below). For more information about the project and event, go to our website:

www.stimrockexpress.org

stimrockexpress@gmail.com

07704 246 555

Jenny Berman Project Co-ordinator (Stim Rock Express) NAS Autism Centre 76C St Charles' Square London W10 6EJ

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