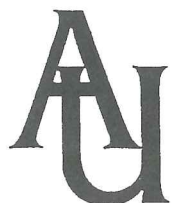
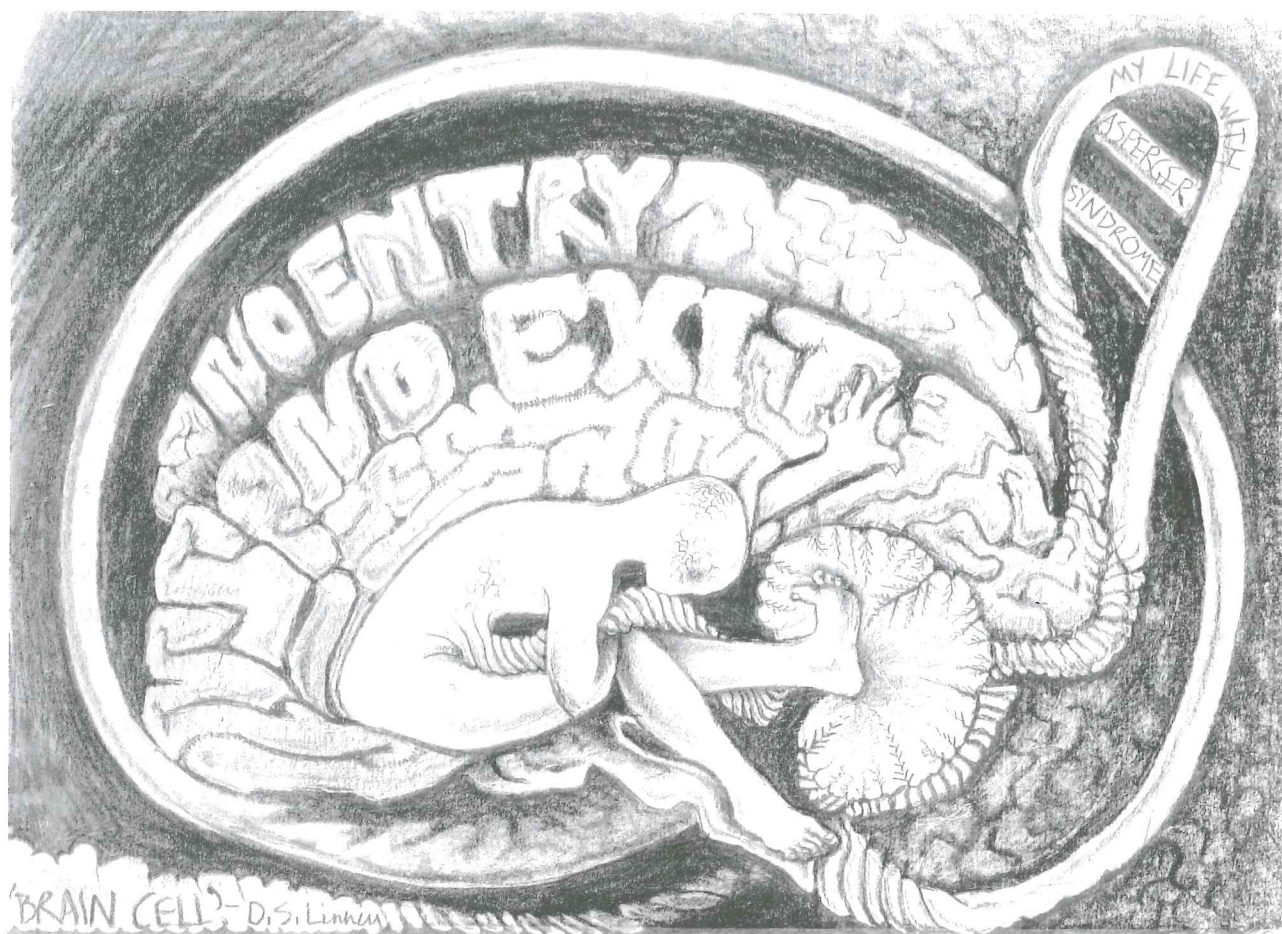


Produced by and for people with autism-spectrum conditions

# Asperger *united*

Edition 62 April 2010





*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 with 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. *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 £6 per year from overseas readers and £10 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 support** The National Autistic Society's Publications Department

**Please send all correspondence and subscription requests by e-mail or post to:**

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Fax: 020 7833 9666  
Email: [asp.uta@nas.org.uk](mailto:asp.uta@nas.org.uk)

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

Thank you to George Cox who kindly produced the illustration included here and on page 6, and 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.*

Contributions for the next issue should reach us by  
17 May '10

*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 Cohen.





**Welcome** to the April edition, and thank you to all those who wrote in, and thank you for your patience while the problems with the new database were sorted out. A few problems remain, but almost all of you should find that things are back to normal.

Some people expressed confusion about which articles and letters were part of the theme of relationships and which weren't. Well, most of them were, including the one about assistance dogs — you can have relationships with dogs as well as people. In fact, "relationships" is a very broad topic indeed, so almost anything can be covered by that description. And remember that writing on all topics is appreciated, every edition, and that art is always welcome, too.

Also, thank you to those who let me know that you hoped that my book reviews would

return even though I was now the editor. I've put a long one in this edition, but will continue to keep most of my book reviews short in order to leave more space for other writers. No one else is limited to short reviews, and reviews of any book, film or whatever are welcome, not just those about autism and Asperger syndrome.

Lastly, some of you may have heard that the American Psychiatric Association is proposing to replace all diagnoses from the autism spectrum with the single diagnosis of ASD. This is because diagnostic experts don't agree on who goes in which sub-category, such as Asperger's and HFA. If anyone has any thoughts on this please write in.

I look forward to hearing from you,

the Editor

## the living edition

If sufficient material is sent in, the theme for July will be **getting a diagnosis as an adult** (or **diagnosis in general**) or **anxiety**. How you felt about your diagnosis, what you think about the proposed changes to the diagnostic manuals, how anxiety affects you, and anything else you think is relevant. For that matter, anything you think is *irrelevant* is welcome too.

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## Turning a relationsh\*t into a relationship

### part two

(copies of issue 61 are still available from the Editor, if you want part one)

by Paolo

Another issue I think that would quash all the issues I wrote about in part one would be if there was complete transparency (no hidden agendas) to decrease fear and also turn love that was conditional into something unconditional. I feel there are thus five levels of truth-telling to achieve this transparency in a relationship:

- The first level is to tell the truth to yourself about yourself
- The second level is to tell the truth to yourself about another
- The third level is to tell the truth about yourself to another
- The fourth level is to tell the truth about another, to that other
- The final level is to tell the truth to everyone about everything — then you will never have to lie anymore.

This transparency would also solve issues of people entering into power struggles in regards to time, availability and the activities of the other. Instead, tell them to do as they wish but also tell them the facts from an assessed observation of the situation, ie. how that disagrees with who you are and what the affects of that are in the long run with you. Thus there's no power struggle when there's no struggle over power. Instead there's only "that what is so" — simply causing each person to remove themselves from the struggle and returning to the place of their own power by allowing themselves to be, do and have what they choose without making the other wrong about it. Thus choose what you're choosing and I'll choose what I'm choosing — this helps one-another make a free-will,

empowered choice to notice that they can control the outcomes of their life by controlling their behaviours. This is therefore how true/free love reacts — it never struggles with power but says that my will for you is your will for you. See the other as they don't imagine themselves to be seen and give everything you are to them, needing nothing in return. But obviously walk away if they start abusing that.

I believe the most loving person is someone who is self-centred. The context I'm using for self-centredness in regards to relationships is that you need to care about your self first before you can help others to care about their selves. If you care about someone it means you love them and obviously if you care about yourself, it means you love your self and that ultimately your self is centred/balanced/in harmony with your soul. Therefore if you love yourself, you will love others. Thus don't seek your love through love for another but ask yourself who am I and who do I want to be in relationship to that. I think it's not about how well the other has lived up to your ideas and vice versa — it should only be how well you live up to yours. You being in a relationship is all that should matter. Through a self-created relationship we experience, announce, declare, express, fulfil and become who we really are.

I feel you shouldn't view a relationship as something/stuff you want to be happy, ie. based on a need for fulfilment as this causes a trade agreement of love. Instead agree on a purpose (as an opportunity of growth) in order to start a relationship. However, relationships should never place limitations on either partner. Love and obligation can't exist



with each other. The more we love ourselves, the smaller our ego is. Relationships based on real/true love are totally and completely free — without conditionality and limitation, eg. my will for you is your will for you.

There is no form in which the expression of love as pure and true is inappropriate, ie. where it allows itself to produce damage to another. Thus love each other in a way that feels pure inside our soul, regardless of gender, colour, religion or any other factors — we are all one and there is therefore only one of us to love.

Stop looking to another for love and see that it's in you. Also stop making each other wrong. People who really love you keep you affirmed in your most daring thoughts about yourself. If you can love yourself, you can love anything. If we saw ourselves as we really are, we'd smile a lot. :)

\*\*\*\*\*

If you found the spirituality in this article very useful, I would definitely recommend reading a book entitled *Conversations With God* by Neale Donald Walsch.

---

### **Autscape: an *autistic* conference**

Radstock, Somerset  
(near Bath)

Tuesday 10th – Friday 13th August 2010

**An annual residential conference and  
retreat organised for and by autistics**

This year's theme is Autistic Wellbeing.

- \* Workshops & presentations
- \* Leisure activities
- \* Meet others with aspergers and autism
- \* Autistic-friendly environment
- \* Childcare available
- \* Full board — 3 meals and tea/coffee breaks included in price
- \* Ensuite twin bedrooms, some singles available
- \* Beautiful landscaped gardens and parkland away from traffic noise
- \* Non-autistics also welcome

Registration opens late April.

<http://www.autscape.org>

Tel: 01606 41200

Email: [info@autscape.org](mailto:info@autscape.org)

Write to:

Autscape,  
24 Anson Road,  
Upper Cambourne,  
Cambridgeshire,  
CB23 6DQ  
UK



## letters to the editor

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### Changes to *AU*

*This letter is typical of the twenty letters AU has received on the subject of changes to the magazine (it is also the shortest):*

**Dear Goth,**

all of your suggested changes for *Asperger United* magazine should be appreciated by all readers.

Just to let you know and thanks for your efforts :-)

Yours sincerely,

**Annie**

---

**To the Goth and all at *AU*,**

just a note to let you know how much the magazine is appreciated . . . the suggestions re the revamp are all sound — including six copies of *AU* per annum! — and would, I feel, enhance the magazine.

The prospect of going into colour is particularly exciting. It would be great to see articles in which Aspies showcased their collections (!), discussed their special interests, etc., including those of music and the arts . . .

The experiences of those for whom late diagnosis can prove so problematic would also be of great interest. Keep up the good work,

kind regards,

**Debbie and Mark**

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**Dear Editor,**

Here is a late reply to your notice in the October edition.

1. I think the use of colour is not environmentally friendly or cost-justified so I would favour the continued use of B&W
2. I agree that moving the word united to the same line as Asperger would resolve the confusion
3. I don't think the small u is too important
4. I agree — Times font is outdated — there are lots of fonts which are more readable and elegant
5. Perhaps it might be possible to provide a special colour version for those with dyslexia
6. I think the current use of lines to separate articles is clear
7. The NAS brand logo on the front page would be a good idea. More white space might lead to a reduction in font size which would not help the readability of the text
8. Perhaps you could explain the procedures on the NAS website instead of in the magazine. This would leave more space for articles
9. Six editions instead of 4: I think this decision can only be made by you as editor.

Best wishes

**Mike**

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*Thanks to all for your responses. To answer some of Mike's points: a second run in colour just for dyslexics would have as big an environmental impact as one colour run for everybody; I want to keep to the Royal National Institute for the Blind's standards for the partially sighted, so the font size won't change; and few readers have Internet access, so info must be in print. I hope to introduce some changes soon. Remember that if enough people don't like them, I'll change them back, Ed.*

---





# 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.)
- To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.
- 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.
- Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*. Only replies from under-eighteens will be forwarded to under-sixteens.
- The NAS pen-pal website has been taken down. What has happened is being investigated.

**\*\*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 68

### Dear Editor,

I am referring to Sam on page 6 of the January issue. I agree entirely, I was finally “diagnosed” as having autistic-spectrum disorder in 2007 at the age of 43 and have had no help whatsoever — except looking at various websites etc. Even my diagnosis was down to myself, having seen various documentaries etc., I realised I had most of the traits. I was born and brought up in remote country areas until I was 16 and just thought I was incredibly shy. School and work were tolerated with great difficulty until several things pushed me over the edge, so to speak.

Unfortunately, Sam, I think if one is a borderline person with ASD and not diagnosed at school, life is very hard and it’s difficult to meet someone well-suited. I’ve had many interests all my life and done a lot, but sadly mostly been a loner.

I would love a suitable pen friend. I have a flat, two cats, and enjoy music, sport, cinema, animals/nature, reading/writing, art/photography, walking/ cycling, TV/DVD/ video, the Internet, ufology/philosophy and visiting North-West Wales,

**Dave**

### Pen pal number 69

**Hello, my name is Joanne,** I am 41 years old. I am looking for a pen pal as I enjoy meeting new people. My interests are swimming, walking, dancing, listening to music and shopping. I live in Accrington in a residential home.

---

### Pen pal number 70

**Hello, I'm Ben.** I am 21 years of age and I live with my mum in Cornwall.

I have many things which interest me. I like writing stories, one of which I hope to get published. I like playing games, reading books, listening to music and watching films, including westerns, comedy and fantasy.

There are other things which I enjoy doing. I enjoy gig rowing, swimming, walking and going to the gym. I'm even going to start climbing. I do all these things because I want to be a mountaineer, so I need to get extremely fit. Becoming a mountaineer is what I want more than anything else in life. My golden opportunity is to lead an expedition of climbers with Asperger syndrome to the summit of Everest. I want to achieve this goal so that I can prove to all people with Asperger syndrome that they can climb Everest just like any other climber.

I wish to hear from someone of similar age to me, who is interested in mountains. But most of all I wish to hear from someone who is willing to be my climbing partner. Then I will have someone to share my mountain adventures with.

I'm really looking forward to hearing from you and I hope we'll meet one day.

### Pen pal number 71

**Hi, my name is Kurtis.**

I am 12 years old and I live in Sheffield with my mum, dad and my sister. I have Asperger syndrome.

I am interested in birdwatching out of my loft window and playing on my PS2. I specifically like *Driver3*. I also enjoy going on my computer and building computers. Sometimes I go on long bike rides with my friends. I also like watching *Top Gear*, *MythBusters* and *the Simpsons*.

I would like to hear from anyone aged 11 to 17. I will read all letters.

---

### Pen pal number 72

**Hello my name is Richard.** I'm 27 years old, a gay man looking to meet, chat to other gays between ages of 28 to 39 years of age. More in common with to talk about problems with having Asperger syndrome and being gay.

My hobbies, interests are playing pool, watching Formula One, running, walking my dog on beach, holidays.

I'm from Devon. I don't really go out. Seem straight-acting, look for similar to meet up, have chat with, a laugh with. I currently have Aspie friends who are straight and it'd be nice to be friendly with gay Aspies. Someone to relate to and talk about problems.

I currently go to speaking-up groups to raise awareness of autism spectrum disorder. With the right help people can lead a better life.



### Pen pal number 73

**Dear Asperger United,**

this is my first written contact with you and I hope you can find space for me in your magazine:

**Hello everyone,**

**my name is Louis** and I am 26. I was diagnosed with Asperger's when I was 17, having been diagnosed with dysphasia (difficulty processing what I hear) at the age of 3. As a result, I went to residential special needs schools where I made some good friends along the way, some of who I still keep in touch with. I currently live in South-West London with my parents, having had a flat on my own for a year, and I now occupy myself with part-time college and volunteer work.

Just over a year ago, I left a residential arts and crafts college in Gloucestershire where I spent three happy years. I forged some strong friendships with other students and I also had

a girlfriend. I became confident there, mainly because I had a regular routine of activities and the other young students had similar difficulties. Since I have left, I have been trying to fit into the mainstream as I'm fairly high-functioning but socialising is very hard. The friends I do have live quite a distance from me and I haven't met anyone locally yet. This reinforces the loneliness I feel. I go to various church groups where people are very caring and friendly but again, most of the people tend to come and go so I haven't got to know people well. I think that's because they are mainly young professionals who lead very busy lives. They are also in their thirties, whereas I would like to meet people of my own age group.

I wonder if any of you readers experience similar struggles of basically feeling that you neither belong to the mainstream nor necessarily a special needs situation? If so, I would be pleased to hear from you, especially if you are in your 20s. I forgot to say that I do calligraphy and love music and play the piano and if it weren't for piano-playing I sometimes think I would go crazy!

---

## Guidelines for churches

Following the quite-a-bit-about-church edition, number 60 in October, several readers wrote in with details of a document that has been prepared with the active involvement of people on the spectrum. Sorry for the delay (the Goth is saying that a lot at the moment) but it was overlooked in the rush to get the magazine out during the database chaos of last quarter.

Some of you might want to point your church leaders and policy makers to this Oxford diocese publication, by way of educating some churches. The denomination of the church may be less important than the general principles involved.

Here is the address for the document:

**[www.oxford.anglican.org/social-justice/just-care/welcoming-those-with-autism-and-asperger-syndrome-in-our-churches-and-communities.html](http://www.oxford.anglican.org/social-justice/just-care/welcoming-those-with-autism-and-asperger-syndrome-in-our-churches-and-communities.html)**

It's rather long and won't fit on one line of the magazine, but at least it's all real words and common Internet abbreviations. The author's webpage is: **[abdn.ac.uk/cshad/memmot.htm](http://abdn.ac.uk/cshad/memmot.htm)**

### Pen pal number 74

**Hello. My name is Vincent.** I am 19 years of age and I like science-fiction and fantasy, particularly Star Wars. I like animation and anthropomorphic cartoons. I was diagnosed with Asperger's syndrome at age 6 and have had over thirteen years' experience with the

condition. I would look forward to anyone writing to me and becoming pen pals. I am very interested in otters and enjoy reading about them. I am an avid reader and enjoy films (not just about otters, ha-ha!).

Look forward to hearing from whoever may reply.

---

### Hi Richard,

I have read with much interest your article on the back cover of the latest edition of *Asperger United* magazine. We have much in common. I am 51 years of age, and like you was diagnosed with AS in 2004. I work privately for a family as their single-handed gardener (and general help) and the family has a lovely 12-year-old English springer spaniel bitch, Polly, whom I have loved for the majority of the eleven years I have been working for the family.

Polly is highly intelligent and loving, as well as in tune with how anyone close to her is feeling. She forgives you when you tread on her tail (or anything similar to that) and really wants to be your friend and companion. Polly's natural cheerfulness and energy, as well as emotional honesty, all help me as an autistic to build up my own self-esteem. For years I was, however, giving this dog treats and thus was "killing her with kindness". This had to stop and when it did, Polly took a good while to cotton onto the fact that there would be no more treats for her from me. But it really came home to me what I had done wrong here when my employer put Polly onto the vet's scales. She was three kilos overweight and so she was placed on a new diet and was not allowed near Bonios any longer: these had fattened her too much. Polly is a gun dog and naturally curious about any smells she may detect but, just like an Aspie, she will not always think of her own safety when going after these. It is hard for me to turn her round after the first half of a walk has ended and it is time to return home again.

What has impressed me has been the many health problems that Polly has managed to get over. One of these involved a horrific wound to the neck which she sustained after sniffing around the compost heap. This is enclosed in wood panels covered in chain-link fence roll, which Polly must have cut herself on — that is, a jutting-out piece of the stiff, plastic-coated wire. When Polly's owner alerted me to this, I was extremely upset and had been at the work place for some five years by that time. Polly has had problems with arthritis in legs, mouth hygiene, and fatty lumps on her body. She has also been sick, coughed up blood, and cut her nose several times. Clearly, medicines have been prescribed for many of these problems but it has also taken a good deal of resilience from Polly to bring about her many recoveries.

Whilst this pet is not mine, my employer has said that Polly might as well belong to me: "she is my pet" and she sits next to my chair at the table when I have my evening meal at work. I give Polly more attention than anyone in the family except for my employer herself. This dog is very alert to strangers and will bark if their smell is unfamiliar to her. Whilst I have been away for the Christmas break, Polly has stood on her hind legs on many days of this break, looking out for me.

I do hope that this gives you some idea of how much I love Polly and how I enjoy to be near her.

**Tim**



## Managing meltdowns

using the SCARED calming technique with children and adults with autism

by Deborah Lipsky and Will Richards

ISBN: 978 1 84310 908 2

£9.99 / \$14.95 Jessica Kingsley Publishers

review by the Goth

There is much confusion over what constitutes a meltdown. It is sometimes used to mean a shutdown, where the person withdraws from the outside world, and it is sometimes used as a polite way of saying tantrum. This book adds to the confusion by restricting the meaning to those meltdowns which build slowly, claiming that that is like a real meltdown, and coining the expression “catastrophic reaction” for a sudden meltdown. For the record, the most well-known meltdown, Three-Mile Island nuclear power station in the USA, took less than two seconds to go from normal reactor operation to unavoidable meltdown, and this is typical of the behaviour of currently operating nuclear reactors when things go wrong.

From my own experience, I would say that a shutdown was a very different thing to a tantrum and tantrums can be real or faked, so I will reserve the word meltdown for a real tantrum. I think a meltdown is a state where you can no longer cope, no matter how hard you try. Your mind then “resets” itself with a meltdown and you can then start afresh.

Some people, including the authors of this book, use the word tantrum to mean the same as “temper tantrum”, but tantrums caused by frustration, fear or overload are identical except in cause, so there doesn’t seem to be any point in restricting the meaning in this way. I think the authors also use the word tantrum to only mean a fake tantrum but they do not make this clear.

It also uses the expression “first responder” without defining what this is. At first I assumed this meant a policeman or a fireman or some such, but one of the anecdotes made it clear that this wasn’t the case. I am aware that this expression has a legal meaning in US law, but have been unable to find such a definition.

Confusion over terminology aside, this is a well-thought-out book which contains much useful advice for helping someone who is having a meltdown, along with tips on how to prepare other people to give you help if you are the person suffering. After attempting to define what a meltdown is, providing plenty of explanation and answering many common questions, the book explains the SCARED technique for dealing with meltdowns. This acronym stands for Safe, Calm, Affirmation, Routine, Empathy, Develop a plan, which covers the six stages that you and your carer need to go through in order to deal with meltdowns effectively. If you do not have a carer, the technique will still be useful but I suspect that most of us would find it difficult to implement without help. Unfortunately, the majority of us do not have a carer that we can rely on in this way, and some will feel their life is better without one.

Overall, a very useful little book which I suggest anyone who struggles with meltdowns can benefit from reading, especially if you can recommend it to your carers and support workers.

## a letter in two parts

---

**Dear Goth**

It is interesting to see what you look like — very different from what I imagined [pale, moon-shaped face, with dark eyes and perhaps face makeup]. That made me think about preconceptions — I hate it when others do this, but it seems I cannot help doing it myself too!

Sorry not many answered about a new style for ASP — I think I did. My only “gripe” — I wish it was monthly, or twice as large, as I really look forward to receiving it.

Now here is my contribution for the “Lifestyle” issue, by way of a “Letter to the Editor”:

**Dear Editor**

Several things resonated in the January issue, which contained a very good selection.

I like the idea of “assistance dogs” for companionship and communication. There was a pilot programme some time ago at a few GP surgeries for giving out “pet prescriptions” instead of pills for depressed people; the Government paid for a cat or dog, vet bills, food etc. I don’t know if that is still going on but what a useful contribution it would make for spectrum disorders — far cheaper than psychiatrists. I shall suggest it to my psychiatrist next time I see him.

There was a recent BBC programme on dog intelligence: BBC HD, 11:30pm Thursday 7th January 2010.

Reader Sam is right — there is very little for adults with AS in Bath and Bristol too. I agree diagnosis usefully explains negative social experiences and this is a huge relief. I don’t feel so alone after a few years living

with an AS diagnosis and am starting to enjoy being non-neuro-typical. I understand myself better the more I read about it — *AU* helps too.

Finally, I hope David will come back with more information on “Contributionalism”. I was discussing lifestyle with my disability employment officer a few months ago. I told him I would be ideal material for a nunnery or monastery — except that I had no religion. I had been considering writing to a bishop to ask if I could be an “autistic anchorite” — but even I thought that might prove too quirky!

What readers say about church rejection put me off that idea. In any case, I wanted to pursue my writing and research interests in peace, whilst being able to engage with empathic people a few times a month [being unable to cope with too much human company].

David’s “psychic lifebelt” is an excellent notion for a lifestyle incorporating support and connectedness, whilst at the same time providing independence and freedom. A group of AS individuals would make an excellent community of dynamic satellites. Just imagine the skillbase as such minds become “unravelling” and relaxed — the collective talent, intellect and potential. A few human “social translators” and “assistance” pets would make it gel.

I wonder if lottery funding might be sought for a building/housing for such a community? It would be, after all, a kind of religious house. I know I would like to become part of such a thing.

Best regards

**Marianne**



**Dear Michelle,**

I'm sorry not to have replied to your letter when you first wrote it. When I saw the editor's reassurance in the January issue about early deaths usually being a coincidence, I felt I wanted to write and respond properly to some of your concerns. I'm a vicar with Asperger's syndrome, I've had cancer, and my mother's family had a history of dying young, so I think I understand some of the things that are worrying you.

I'm sorry to hear that communication with your mother's side of the family is so limited: the same has happened with my wife's family and us, and we really don't know what has happened to most of them. AS, especially undiagnosed, can hamper communication, but sometimes families are just plain odd, I'm afraid! And you are exactly right, any kind of "difference" used to be (for some people still is) something to hide away from the rest of supposedly "normal" society.

Jumping to the end of your letter, statistics about average life duration, about women living longer than men, and so on, are only averages, covering up the fact that some people live a lot longer than others. Sadly, others still die younger than average — I know, I nearly did myself! And I think the editor is right, coincidences like dying at the same age do happen, and we shouldn't treat them as any more than that, coincidences.

"Can people with autism/AS die young?" I think the experts would tell us there is no necessary connection between autism and dying young, but I would like to make a couple of comments here based on my own experience, because I think it's sometimes true that people with autism/AS may not get the best and promptest medical treatment when illnesses develop.

1. Sometimes we may not be good at communicating with the doctor when we feel ill. This can be because of struggles relating to other people, and sometimes because our senses aren't so "tuned" to report the exact location and nature of pain or discomfort. If we are too vague, some doctors may dismiss our concerns as "anxiety".

2. If we are anxious or very "private" people anyway, then anxiety about an illness can paralyze us just when the discomfort should be spurring us to seek help. We may dread the illness, or dread some of what might be involved in getting it treated. If the illness is serious, we need to find a way through the anxiety in order to get treatment. You'd be amazed what one can put up with when there is no alternative!

3. If we have sensory deficits, the doctor may mistake the seriousness of our condition because we don't report "enough" pain! My doctor is now aware of this factor, and knows that when I report pain it is likely to be something another person would find very painful indeed!

4. Finally, sadly, some members of the medical profession pay less attention to the needs of autistic/AS patients because they have a stereotyped view of our needs and potentialities. This attitude is dying out, thankfully, but unfortunately it hasn't completely disappeared yet.

Michelle, I hope that helps a bit. Try not to let anxiety about tomorrow overshadow the good things of today, and try not to worry about health, but equally try not to neglect it either!

Best wishes,

**Chris**

## Tongue-in-cheek reflections of mindless madness

or

### Living: part of this Aspie's point of view!!!

*Note: this piece is best when heard, rather than read. A lot of people have difficulty understanding poetry, but that's sort of the point of poetry: it's meant to try to communicate difficult things that require thinking about. The layers of meaning are not obvious, but hopefully they will become clearer if you reread Tracey's poem. Please be aware that some of the imagery is quite graphic, Ed.*

Multitudes of rapidly moving mouthparts greedily chomp on the mute motionlessness of a silky smooth day-dreamy day. Thus, alas, as fast as the speed of sound in transit can travel, the masticated air is a cacophony of chewed up regurgitated reverberations, spat out as noise vibrations that come hurtling and gormlessly gorging at the oval window of my inner ear . . . where hammer and anvil are primed and prepared to perform the tedious task of forging the blacksmith shoes that shod their horses' harassing hobnailed hooves. By luck, but mostly by design, their pounding stampede is impeded by my barricades of strategic secretions of compacted wads of wax. But still their thronging blitz bays and clamours and knocks and hammers to be admitted and heard like a herd of squawking babies, helplessly screeching with their blue oxygen-drained lungs — for absolutely any reason or absolute zero no reason. Many unhappy crapped nappies ago these babies outgrew their swaddling clothing, worn to restrict, it's worked its wondrous wounding trick, now afflicted with stunted growth excessively well inflicted. Consequently they are doomed to remain suffocating and swamped in black and blind garbage bags, marinating underfoot in swelling and steaming and stinking and heaving landfill pits of unnaturally plastic-packaged shit. They are slap-happy blind to all that they shovel under natures' unsumptuously deep-piled rug . . . until she bites back in a mother of all mothers eruptive hurray way. These bonsai adults are brainwashed and bound and tightly trussed up as handicapped and malignantly mad cows and a load of bulls . . . spouting their hazardous

bails of poisonous baloney. B\*\*\*\*cks, bullocks and heifers fenced in fields as fodder feeding and fattening up too synthetically fast — pushed and rushed along the processing conveyor belt of their express train journeying lives, quickly zooming past in a slaughtered flash. Anti-nature, they force-feed on scraps of each other . . . beef cannibalistically grazing on beef. Their rampant ringing in my fed-up and ferociously biting-back ears is simultaneously and hypocritically pontificating and professing their oh-so-virtuous values . . . blowing their own out-of-tune trumpets down my boiling-kettle-drum ear drums. They scream out their danger-laden decibels that clank around and around in closed circuit circles — confined and secure . . . and supposedly sane . . . locked in make-believe safe-haven sanctuaries of stolen ivory towers that the elephants want returning — with maximum pay-back interest grossly included — paid in the gross form of:

1. Hacked off human heads mounted and hung on unheeded hooks on the walls of the elephants' invisible zoo.
2. Amputated and split-open human torsos spilling their gorged entrails, emptied, hollowed-out and cured as reproduction elephant-leg umbrella stands or footstools.
3. Human bones picked and stripped bare and bleached and carved into ornamental nonsensical knick-knacks for the elephants to watch or harshly fondle with their previously delicate and docile wild trunks.



And still the air is not silent and still . . . on and on and on rings the continuous distorted din of mangled molecules of air. Their incessant infantile ranting and raving unnervingly persists, accumulating and incrementally mentally amplifying, beating on the war-path drums of my hitherto unresponsive ear drums, so far long-ignored with the unhearing aid of my rebel waxwork repellent blockade. Their manic mandibles prattle and babble as they protrude from the soap-box preaching pulpit supports of their puny human body stalks . . . sermons for me to nonchalantly swat with a blunt flat-line frequency of no thought . . . I wish. Their swarming busybody babble buzzes and bustles and bounces off the walls of my cussed and two-fingered gesticulating barefaced brain, where it rattles and revolves recklessly around and around the inside of my reinforced titanium armour-plated cranium. Their orbiting pernicky nit-picking jeering is much too keen on constantly criticising and finding further faults or ravines in the geography and contours of the under-fished fissured cortex of my convulsing something-is-the-matter grey matter . . . deeply displaced by a giggling-attack unfitting fit . . . retorting to their noise with nervous and incongruous chuckling and chortling, until blood-enflamed and totally tickled shocking pink, choking on its own dry-as-a-sun-soaked-bone sense of poker-faced humour. And still they continue to scratch and rat-a-tat-tap and bang on the surface of the deeply disturbed and parched terrain of my brooding and dried-up-sponge brain. Like plagues of infesting insects crawling and burrowing beneath my already unpalatably scarred skin. They glare serious and thirsty at me the freak with myriad searing compound eyes that are dry but have no sense of humour, so they pierce and suck all the vitreous humour from my wet squishy eyeballs, leaving them lifeless and dull as wizened prunes or slugs marooned and baking and shrivelling in the sun. Their over-active manipulative mandibles are mutated

mechanical and unstoppable JCB jaws. My eye-pits are vacant sucked-dry sockets; my ears are hacked off and stuffed in the double-breasted jacket pocket of Saturn the timeless teacher, whose self-controlled hand slips inside the darkness where it holds tempestuous desire tightly secured under cruel-to-be-kind disciplined restraint, as my bleeding wet-behind-the-ears hacked off holes still gush with blood and coagulating desire; my brain is bombed-out and bombarded beyond bothered. So I dive down to the bottom of their black-tarred barrel, where I bite on my ever-cocked suicidal bullet, and surrender, and let the insects invade and chomp to their nonexistent hearts' content. They munch on the stagnating, though serene, stillness of yet another thought-logged empty void and abandoned day, that the teacher nearly rescued from its fate of being white-washed and pissed away once again in the tempest of my invisible acid rain — down the gutter-trodden drain . . . sodden, saturated and abundantly overflowing with at least ten thousand dumped days of white-crap-noise and cowcatcher-deflected words — ploughed down at point-blank range, smashed and shovelled far out of the way . . . flushed and pumped with relief out into the angry ocean, waiting, for yet still more shit. I stand at the edge and am happy to see the cliffs are alive and cloaked in nature's finest wild and free robes that human insects can't grope. Then I look down and am sick to the depths of the sea that beckons to me to meet with its untamed end . . . sick to my belly pit that heaves and thrusts in convulsions down the full length of my 30-foot recoiled snake-skin skinned intestines. With a surge of guts pulsing through dilated veins, I seize this moment, and within a leap-of-life flash I am mashed and split and spewing out my blood on the rocks beneath, as all the frowning insects scurry out to drown — unwittingly — forming a floating wreath. And whatever is left, laughs, as it seeks and finds another willing cheek in which to stick its biting tongue.

*All magazines have a problem with what to do with small bits of white space, like the one the Goth has filled with this notice. So if anyone has some very short epigrams, aphorisms, poems, mini-stories or anything else that could fill a space like this, please send it in, Ed.*

**In January's edition of *Asperger United*,** Sam raised his difficulties in being understood by others whom he told he was Asperger. When I was diagnosed several years ago I was given little information on what to do with this diagnosis. Particularly as I was going through a "crisis" at work as a result of bullying management (I subsequently lost my job), I needed help adjusting to this information, but was not given such help. I had to find out about Asperger's for myself. I joined an Asperger group (the one run by Autism London) and I read up on the subject. Despite Sam's comments, there are courses, etc., for Asperger's — if he lives near London, I would particularly commend the ones run by the Asperger Syndrome Foundation which are free to those with Asperger's. I am far from an expert on Asperger's and still often find myself learning new things, but an understanding of Asperger's helps me understand myself and how I differ from others.

Regarding dealing with friends, etc., those who deny Asperger's existence are, like holocaust deniers, beyond the pale, and are best ignored. Moving on from these, many other people have little or no understanding of autism (before my diagnosis, my only knowledge was the *Rain Man* film and I was convinced I did not have Asperger's as I was not like him!). You need to explain it and, as far as possible, in a positive way. It is not "wrong" to be Asperger and in any event you were born with it, so you cannot be blamed. Although it is classed as a disability and in

some aspects we are disabled, we also have a lot of positive aspects to offer. When you contribute something important to a discussion which is evident to you because of your Asperger thought processes, prove to be a good quiz team member as you have a good memory, etc., point the connections with Asperger's out. When appropriate explain your behaviour in Asperger terms, eg., "Because I'm Asperger, I'd get bored spending all evening in the pub, but I don't mind popping in for an hour". There are many famous people who have been diagnosed as probably Asperger's, eg., Beethoven, Mozart, Einstein, Isaac Newton, Jane Austen and Alan Turing and citing such examples will help people appreciate that we do have something special to offer society.

Finally, do not forget that you are still the same person you were before your diagnosis, but now your differences have been conveniently "labelled". You will have a reasonably good idea of what your strong and weak points were pre-diagnosis, but your diagnosis will probably make the reasons for some of these clearer. Do not be afraid to be yourself as "God" (if you believe in him) created you. Sometimes others may think your behaviour odd or eccentric, but hopefully an Asperger label will help them understand these differences.

Regards

**John**



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