

Produced by and for people with autism-spectrum conditions

Asperger *united*

Edition **58** April 2009





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 John Joyce

Additional support The National Autistic Society's Publications Department

Please send all correspondence and subscription requests to:

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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 newsletter.

Contributions for the next issue should reach us by
18 May '09

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 provision 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 and the current editor, John Joyce.

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*, suggested by Anna Cohen, was chosen by the group of original readers as the most 'appropriate name' for the publication.



Dear readers

Welcome to the new edition of your magazine. Hope you are all well as I am.

Big news for you. In October this year I reach 65 and propose to leave this job to a more skilled journalist than I. Over the past twelve years you have provided very good copy and I hope this continues into my successor's reign.

In one of my activities I am required, because of the Secretarial office I hold, to attend a Diocesan Council meeting once a month. In ten of the twelve months of the year this requires a whole evening away from home on the third Monday while in the other two months the same meeting is on the third

Sunday afternoon. The February meeting gave me centre stage to report on the Croydon Curia of the Legion of Mary.

I shall again be booking for Lourdes shortly. Do any of you have a holiday planned or have you recently taken one you could report on?

May I take this opportunity to thank all who have contributed to the success of this periodical since it first appeared in 1993 either as editors, writers, consultants or compilers.

Best wishes for Easter

Your Editor

John Joyce

The theme for July will be **work** (including unemployment). Writing on any subject is still welcome, so get writing! (Cover art is also welcome, but please note that the printing process requires strong contrast between dark and light.)

the absences edition

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Absences

letters in reply to John's letter (the first John) in last issue — there was such a large response that this clearly needed to be the theme of this issue

I would like to respond to John, who was asking about his son's lapses of attention, "absences".

I am 45 years old and frequently had this happen to me from the age of 11 up until my early twenties.

I was finally diagnosed with AS when I was 34, after doing a degree in psychology and realising that autism explained my experiences.

Like your son, I was also tested for epilepsy (*petit mal*) as a child and this was ruled out.

It would typically happen when I was surrounded by people, in social situations. I would liken it to falling asleep.

Except people I was with would tell me that my face would go blank and I would be unresponsive for several minutes.

I would then come to and continue as before.

Interestingly, on the same page as your letter, *Asperger United* edition 57 page 6, another John mentions hyper-systemising.

This I think is also linked to my experience of "absences" and your son's.

My hypothesis is as follows. At any given time there is a huge amount of information coming in through our five senses. Far too much for us to process at the same time.

The only way to cope with this volume of information is for us to switch our attention to

the relevant information, eg. sight or sound.

In neurotypical people (non-autistic) this process seems to be largely automatic. In autistic-spectrum people this doesn't happen as efficiently for some reason. I believe that this causes an overload of information.

This can be compounded by the autistic person at the same time trying to make sense of the behaviour of people around them, another process that is automatic for neurotypical people and not for autistic people. The brain can respond to this overload by temporarily shutting down. Hence the "absences".

When I was 21 I got a job in a pizza take-away. As part of the job I of course had to deal with people. I also had to make pizzas in the shop whilst being watched by customers. I found this very stressful and had many "absences". I found a solution to this that worked for me. I would empty my mind and function largely on automatic. This seems to have largely cured the problem, although it does still happen occasionally.

This technique can obviously itself cause problems. In as much as it takes me longer to react to a situation than other people and I am not as aware of my surroundings as I sometimes should be. This understandably has caused problems in jobs. I can focus on things I need to, though, consciously.

I hope this helps.

Regards

Iain

I have had absences since I was a child.

Always they involve complete loss of all senses and conscious thought. Sometimes I stop completely still when they occur and sometimes (although very infrequently) I am able to walk. In the last year I have noticed that these "absences" occur much more often when I have too much to do. Consequently they could be my brain just having a rest. The alternative is a mild form of epilepsy. Currently a neurologist is trying to establish which of these two occurs in my case.

Elizabeth

I experience lapses of attention in

conversation, and also less clearly definable blanks in the daytime. I did pursue epilepsy once with my GP but this was ruled out, and I frequently asked close family to find out what they observed. When I'm engaged in something that really interests me I don't appear to have blanks. I do a lot of research where I'm completely absorbed, where time seems to pass quickly, but I cannot identify any breaks in activity. Similarly if I'm interested in conversation I don't have blanks, but they are embarrassing when they occur, as I then have to try to read between the lines to catch up.

Tom

Please note that some people chose to write private replies to John, which have been passed on, and that printed on these two pages are all the open letters received by AU. Further responses are welcome, Ed.

The condition being described appears to be non-epileptic seizure. A GP or consultant can refer people for a formal diagnosis. The National Society for Epilepsy publishes a leaflet with more information, and has a helpline which people can call for advice — **01494 601 400.**

Anon (left a telephone message with no name or address supplied)

I have episodes like this, which appear to be stress-related: not the stress of the moment, but stress from a more prolonged period of days or weeks.

My thoughts are often non-verbal, and during these episodes they always are. Sometimes I can remember non-verbal thoughts, but mostly they are quite difficult to keep hold of. From talking to friends, I get the impression that for most people non-verbal thoughts are extremely difficult to remember and, of course, they are very difficult to talk about. This can lead to a sensation of having a memory blank or absence when my focus moves away from my thoughts and back to the outside world.

I have successfully crossed busy roads while "absent" (though I have occasionally been hooted), so please be reassured that, if John's son can conquer the fear and disorientation, he will be safe. I suspect both the internal focus and the residual danger-awareness are survival mechanisms, but of different kinds.

Nemo (name and address were supplied to AU)

The books reviewed on pages 9 and 14-15, are available from Central Books Ltd, the book distributor for the NAS, tel: **0845 458 9911**, on line at **www.autism.org.uk/pubs** and can be ordered from all good bookshops. **Special offer:** readers can get copies of these

two books post-free until 31 May 2009. Just send your order with a cheque made payable to

The NAS
393 City Road
London
EC1V 1NG



letters to the editor

Comment on Louisa's letter and J's response

I don't know if this helps, but it has been useful to me. A long time ago, I told a friend of mine how I felt rejected in a similar manner, when friends did not contact me or went away. His response was to think of people you meet as passengers on your bus. They sometimes stay on the bus for a long time, before getting off. Sometimes they get off only to return at another stop. Sometimes you only meet them once — they get off the bus to see new sights and you never see them again. It does not mean they no longer like you, just that their journey has taken them elsewhere.

I recently contacted this friend, but a relative of his wrote and said that he was no longer with us. He is now on "the celestial omnibus". I wished I had contacted him and his wife earlier but it was not to be. However I have happy memories of many "bus rides" together.

Marianne

PS. "The celestial omnibus" is not my phrase, but the title of a lovely short story by E M Forster, which readers might enjoy.

Dear AU,

I am writing in response to the letter in the October issue by L Haag, as I live in Cornwall.

I have recently been diagnosed with Asperger's, along with my eight-year-old daughter. Eight months ago I tried to get help for her with sensory issues. They were becoming more apparent as she got older and was able to vocalise her problems.

Wherever I went I was barely listened to and not believed. The headmaster of her school called me an "inadequate parent", social workers came and shouted at both of us, saying we were making it all up. We eventually got an appointment with the local CAMHS. The doctor there did not even meet my daughter — she went into a play area with a nurse whilst the psychologist asked me a few questions. It was perfectly clear that he did not believe me, and a few days later there was a child protection conference. A social worker gave completely false information and twisted what we had both said. Shortly after that I was taken to court. I have been back again and again for different hearings. In the end I asked that my daughter be sent to live with her mother. By this time her state of mind had deteriorated by

constantly being shouted at by social workers. (At one point they dragged her screaming out of my house half-dressed, cutting her foot and ripping her jumper.)

When she was with her mother for a couple of weeks, they persisted in not believing her and eventually traumatised her so badly she was hospitalised for two weeks. Whilst in hospital she was given an immediate diagnosis and is at last getting the help she needs. A psychiatrist was appointed by the court, and she made an initial diagnosis of both of us. We are still waiting for her final report.

We are still going through the court process where I am struggling to even have contact. You would expect the so-called professionals involved would at least apologise, but not a bit of it. They turned a bouncy, happy little girl with a unique sense of humour into a fearful timid girl who would no longer go to school or to friends, etc.

So, from my point of view, the more publicity given to Asperger's, the better, as I believe that even within the NHS it is unheard of, especially, it seems, in Cornwall!

Yours sincerely,

W Byrne



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.)
- 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*.
- If you prefer, you could try the NAS pen-pal website, which is at www.assists.org.uk/penpal.html Please note that ASSIST (which runs the website) is entirely separate from *Asperger United*.

****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 49

Damian.

I am 34 years old and based in Nottingham and am looking to expand my social network. I'm very interested in the arts, particularly in the theatre and classical music. I've done a lot of amateur drama over the years, took drama classes as a teenager and really enjoyed it. My main interest is in languages and the ancient world;

I taught myself Latin a few years ago and am now working on ancient Greek. It's quite a challenge but one which I find very rewarding. I have only recently been diagnosed with Asperger syndrome and I'm still trying to work out what it means to me so I'd be interested in contacting, and eventually meeting, like-minded people through this forum.

Pen pal number 50

My name is Amber, I am 48 (late diagnosis). I'm an artist/painter. I read a lot and write a bit. I like walking, conversation and music. I'm fascinated by animals and thinking of getting a small dog. I'm new to the Sheffield area and hope to hear from people with similar interests hereabouts and near to it.

a letter and another pen pal

I'm a 20-year-old high-functioning woman with Asperger syndrome. I'd like to share an experience I had relating to knowledge of Asperger's within the health services.

I recently underwent day surgery for wisdom teeth removal. Overall, it went pretty smoothly, as experiences like that go, and the nurses and surgeon were pleasant and helpful. Although they did not seem to have much knowledge of AS, they listened to me, were pleasant and explained what was going to happen and when, without being patronising (for me, knowing the details of what they will do and in what order helps a lot).

However, one quote by the anaesthetist sticks in my mind. On her visit to the ward before the operation, she looked through my notes and medical history and asked: "And the Asperger — is that controlled?" As if it was a mental illness, or something to be ashamed of. (Not that mental illnesses are something to be ashamed of.)

I managed to keep calm and explain that Asperger syndrome isn't something that needs to be controlled; it's part of who I am! I really don't think she meant it in a nasty way; it was out of ignorance.

But it exemplified the ignorance of Asperger syndrome there still is within the health and social care services. (And this is certainly not the first time I've encountered it.)

A simple example of a better way of asking a person with an ASD about their condition in these circumstances might be: "Is there any way we could help to make things as easy as possible?" It doesn't require the professional to have a great deal of knowledge; listening to a person individually is often the best help anyway, and people with ASDs are individual, as anyone is!

Lizzie

Pen pal number 51

My name is Becky. I am 25 and live in a care home for people with Asperger's. I have a *terrible* obsession with writing letters and I'm very interested in pop music so I'd like a pen pal who writes pop songs to send me their songs on tape or CD so that I can write back to them about them and divert away from the obsessive letters. I don't want to write to my pen pal about anything else as I say I need to get away from writing letters and my parents are always encouraging me to write essays, which doesn't help as essays are very like letters so I'd like a pen pal of about my age and it can be a boy or a girl but I don't want to write to them replying to what I think of their pop songs and nothing else. The music of the songs my pen pal sends me must be pop as that's my kind of music and I can send my pen pal my poems, as I write poems hoping to be a lyricist for pop songs and I'd like them to reply to these too but all our correspondence must be about our pop songs and lyrics and no other subjects to get me away from obsessive letters. I hope that there are people out there who'd be interested in sending me their pop songs and if they could set my lyrics to pop music, that would be a bonus as then I'd have a chance of getting them published and of course I'd wish them the best of luck in getting their songs in the charts too. If someone just writes lyrics and wants to send me those that's fine but that would take up all our correspondence. It would be better if my pen pal wrote pop music too as then I'd have a chance of getting my lyrics published but I look forward very much to hearing if there's anyone who would be a suitable friend for me by post so if you write pop songs and you'd like to write to me as a friend who needs your help and shares your interests just send a letter to me and I'll see if I think you'd be a good pen pal for me and I'd be *delighted* to hear from anyone who thinks they're suitable for me so I hope there are loads of people interested in being my friends and helping me with my problems that I so definitely need a friend like I've asked for.

A self-determined future with Asperger syndrome

Solution-focused approaches

by **Veronica Bliss and Genevieve Edmonds**

Jessica Kingsley publishers £12.99 / \$18.95 ISBN: 978 1 84310 513 8

review by **the Goth**

From an initially unassuming title I wasn't at all sure what I was going to make of this book, but immediately on starting to read, the thinking behind the title is explained and the basis of the book on solution-focused therapy is explained. It is wonderful to realise that there are people working with autism who have this very useful and effective mindset in how to help us.

The book is filled with tips and clear examples of how to communicate, and these apply to you whether you are a person trying to help or an autistic yourself. Although be warned the book is also quite humorous, so some parts may be confusing.

Veronica gives examples of how she was trained to think as a young psychologist: she contrasts this "doctor-focused" approach with the solution-focused approach which she now advocates.

The authors boldly define autism in its own way, ignoring traditional diagnostic criteria

and, given recent advances in the understanding of brain function in autists, I think we will see a change in diagnostic criteria coming through the diagnostic system. This will, of course, probably take ten to twenty years. For an accessible article on this, see the 20 September 2008 edition of *New Scientist* or at www.newscientist.com where the same article appears dated 19 September and with a different title: *Do supercharged brains give rise to autism?* Further discussion and articles on this subject can also be found on the *New Scientist* website.

The book does a very good job of describing just what it's like to be autistic when coping with all manner of situations from shopping to receiving a compliment to just getting through an ordinary day in the house. It then provides techniques for learning how to cope with these problems more effectively, although I think they will be quite hard to use if you don't have someone to discuss them with. Nevertheless, a very useful book.

Sleeve

by **Dan**

Did I say the wrong thing, dear?
I need to make it clear
I never meant for you to hurt;
You've cut up all my shirts
— It hurts because I kept my heart on that sleeve

Request for research volunteers

To explore whether adults with Asperger syndrome have mental health needs

Are there social factors that could affect the mental health of adults with Asperger syndrome?

Research involving adults who have *not* been diagnosed with Asperger syndrome has found that there is a relationship between social comparison and mental health, and between social support and mental health. Research involving young people (aged 10-16 years) who have Asperger syndrome has also found a relationship between social comparison and mental health. (Social comparison is the ability to compare your opinion and achievements with others, and social support refers to support received from your social network, for example, family, work/college, health professional, etc).

The purpose of this study is to try and find out if the same relationships exist in adults who *have* been diagnosed with Asperger syndrome.

This study will also seek to explore whether age affects mental health. For example, is there a time in life when a person might be more vulnerable to mental health difficulties?

It is my sincere hope that the findings of this study will help to develop better ways of relating to adults who have Asperger syndrome.

If you would like to help in providing a better understanding of the mental health needs of adults with Asperger syndrome, then I would be grateful for your help.

Your participation will involve completing an online survey. No personal details will be identified as yours, and therefore your information will remain anonymous.

To take part, please go to the webpage link that appears below. This will take you to my study webpage where you will be able to find the following:

1. The study information sheet
2. The study questionnaire

Please read the information sheet and then complete all the survey questions as well as you can. Thank you.

Please note: to take part in this study you will need to be over 18 years of age and will need to have been diagnosed with Asperger syndrome.

Webpage link:

<http://tinyurl.com/66guhw>

For further information, please contact me at the address or email given below:

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This study is part of a doctoral thesis that is being undertaken by Rachael Blood at the Oxford Doctoral Course in Clinical Psychology. This is an NHS course that is validated by the University of Oxford.

My view of the spectrum

by Vincent

Autism is a neurological variation, not a disease. Because every human is a human being, they deserve the same dignity and respect as other people. Autism is not negative, it can also be positive — many people with autism can achieve great things in science, mathematics, writing, and art. They are also logical thinkers and can be overly literal, so many people think they have no humour, but they do have their own kind of humour unique to them. Many people think that autistic people do not have emotions. Actually, they do, but they don't express it in the same way.

Unfortunately, many works written by professionals create the public opinion that autism is a tragedy. Due to the public perception of people with autism, many people use physically and mentally harmful therapies to treat autism. For example, the Judge Rotenberg Centre in the USA uses electric shocks on autistic people. Some people have used the extremely offensive term "mad child disease". These therapies would be called "torture" by the

neurologically typical. The view that autism is a tragedy is extremely damaging to autistic people who know who they are. Some people even take these further, using phrases like "worse than cancer and 9/11 combined". Even teachers can defame autistic students, considering them arrogant and spiteful.

People with autism have often been bullied and defamed in public due to their eccentric behaviour, precise language, unusual interests, and not responding to indirect communication. Most people with autism want to be social, but fail to socialise successfully. They could have problems with authority figures, because these people describe an autistic child as a "problem child".

For those who do not know what autism is, it is a neurological variation characterised by severe and sustained impairment in social interaction and nonverbal communication. There is a whole spectrum of these psychological conditions. The three main forms are autism, Asperger syndrome, and PDD-NOS (pervasive developmental

disorder — not otherwise specified). People who have autism have restricted, repetitive, pedantic and stereotyped activities, interests, speech and routines. They can have low tolerance for what they see as mediocre tasks, such as homework assignments.

People with autism have always been forming an emerging culture. Like all cultures, it has common beliefs, literature (such as *Look me in the eye* by John Elder Robison), art, and a tendency to marry in the same group, and some terminology used by those in the autistic culture. If these people were to be cured, it would wipe out the entire autistic culture, destroy the person they are, and replace it with somebody else.

Many of us believe in cultural diversity. It's time to support neurodiversity (tolerance of people regardless of neurological wiring). If there is nothing wrong with cultural diversity, what's wrong with neurodiversity?

If you are interested, try researching more about autism.

The melted ice-cream

by Elizabeth

It was a hot summer's day in the early nineteen-sixties. In a busy harbour village, ships and little boats rested at their moorings and visitors thronged the quayside and pier.

In an old terraced cottage overlooking the harbour, a mother and three children looked at the view from a downstairs window. The ice-cream parlour looked inviting.

"Why don't we all have an ice-cream?" said the mother, knowing the idea would be popular. "I think Lizzie might get them on her own today. Would you like to?" She added, turning to the youngest, a little girl of about five years old.

Lizzie was delighted. It was just a short walk down the slope to the lock gates, cross them, up the other side through some parking spaces and up some steps to the ice-cream parlour. Easy. She had done this dozens of times before with one of her older sisters. The entire journey could be seen from the cottage window and her mother and two sisters would be watching. There could be no problem.

Her mother might have said, "Take care crossing the road," as an added precaution, but had certain notions about child-rearing that often confused poor Lizzie. She thought that in order to "get through" to a child, it was necessary to be as verbose and as melodramatic as possible. Her instructions, then, went something like, "Go straight there and straight back. When you come down the steps on the way out, stop on the bottom one and look up the road! Don't step off the bottom step if you can see just one car coming down the road! If you put one foot on that road when you can see a car coming

anywhere, you might be killed! You won't go again! I won't be responsible if you get run over. Stand on the bottom step! Do you understand?" etc.

Lizzie was used to her mother's melodrama. Fortunately, the road led straight to the parking spaces and a sea wall, so cars were always driven at walking pace. She could have handled this perfectly well without her mother's instructions.

Unfortunately, the instructions seemed to include an additional test of obedience. Not being allowed to step off the bottom step of the ice-cream parlour if a car was in sight seemed daft to Lizzie, as the road down the village was a long one. Most cars coming down it invariably turned off to their right before they even reached the harbour.

It couldn't be helped. She wouldn't be sent again if she disobeyed her mother that was clear. She would do her very best to get it right.

Clutching four ice-cream cornets together in her little hands, she walked down the steps and stood on the last one. A car went past. She waited and was reassured by the distant faces of her mother and sisters at the cottage window across the harbour.

She looked to her left. A car could clearly be seen some distance off. She knew she had plenty of time to cross safely but remembered her mother's instructions, "If you can see just one car coming down the road . . .". She glanced across the harbour at her mother's face. Yes, she was definitely watching. Lizzie had better keep to the instructions.

The ice-cream responded to the heat wave in the only way it could — it began to run down the cornets and over her hands. She became confused. Was there a point to this instruction?

Two kindly ladies, walking past, stopped and asked her if there was anything wrong, as the ice-creams seemed to be melting away. "It's alright" she assured them, "My mother told me to do this and is watching from the window."

They looked confused. "The ice-creams will be ruined," one of them said.

"She said if I could see just one car coming, I must stand on the bottom step," Lizzie explained with some embarrassment. She could see it was stupid, but her mother's instructions sometimes were. She still had to obey them.

"But the cars are some distance away and turning off" said one of them kindly. "Would you like to cross with us?"

"No thank you," she replied. "I mustn't talk to strangers or cross the road. My mother is watching." They glanced doubtfully across the harbour and realised the case was hopeless. In truth, they distressed her. Here she was in a situation her mother hadn't anticipated, ice-cream melting over her hands and talking to strangers.

Thankfully, the road through the village was never particularly busy and Lizzie eventually made it across. She arrived home with four sticky cornets and two sticky hands. The ice-cream on top had all but vanished.

Her mother and sisters were dismayed. "Why did you stand on the step and let the ice-creams melt?" demanded her mother. "You were over there talking to people. We don't know them."

"You said stand on the step if I could see a car coming," Lizzie reminded her.

"I didn't mean cars that were miles off!" exclaimed the exasperated parent.

"You said not one foot on the road if I could see a car coming," replied Lizzie, "so I didn't."

"Yes," she replied.

"What did those people say to you, anyway. They must have thought you were a silly nitwit!" said her mother.

"Yes," she replied feeling resentful. It didn't occur to anyone to match her actions with the instructions that she had been given.

This was all too much for Lizzie's mother. She walked away to put the ruined ice-creams in the bin, muttering, "Well! That girl's a bit dippy!"

Here was the difficulty for Lizzie: if she disobeyed her mother, however unreasonable her instructions might seem, she was in trouble. On the other hand, there were occasions when disobedience was positively required. How could she know when this was? She certainly had no idea. It would be down to a lucky guess. Life would be difficult for Lizzie.

By the time she reached adolescence, her mother's efforts to "get through" to her had degenerated into violent outbursts that would leave Lizzie physically stunned and reeling. But all that was still some years away. For now, it was just the odd humiliation and a simmering sense of injustice.

She would be in her forties before she found a permanent home of her own and the peace she craved. A solitary life away from the torments of the human race. A peaceful rural idyll.

Asperger's syndrome and mindfulness:

taking refuge in the Buddha

by **Chris Mitchell**

Jessica Kingsley Publishers £13.99 / \$19.95 ISBN: 978 1 84310 686 9

review by **autiste Ruth**

The subject matter of this book is close to my heart: I have found Buddhist teachings on the mind and awareness of thought processes to be profoundly transformational in my life. For 18 months I was ordained in the New Kadampa Tradition, which I unfortunately discovered to be a borderline cult organization, but I still experience in my life many benefits from the clear structure of Buddhist training with regard to the workings of my mind.

At first I was a little disappointed with this book, having expected more about the qualities of autism spectrum people that lead so many of us to Buddhism. But the book is actually excellent, and presented in a way that is accessible to people of any religion or none, not just to aspiring Buddhists. Don't be put off by the reference to Buddhist refuge in the title.

Mitchell takes some of the basic Buddhist thoughts about life and the mind, and how to improve one's experience of life by learning to observe and work with and within our own minds, and applies them to some tendencies shared by many on the autism spectrum.

In each chapter Mitchell takes a principle or set of principles from Theravada Buddhism, shares some personal experience and an overview of how it can be useful to autistic people, and finishes with sets of around three points of things to consider and think about whether/how to change.

The book confirms what I personally discovered in Buddhism: that making drastic

changes to oneself and one's outlook is not impossible for the autistic, despite that we might think it would be dramatically harder for us than for non-autistic people. In fact the ideas and observations of the mind are very useful for spectrum folk, who do not usually naturally have all that much insight into our own and others' behaviour and thoughts.

For example, under the heading "Discipline and Routine" Mitchell writes about Aspies and change: "As many people with Asperger Syndrome may understandably feel comfortable in a particular routine, it is helpful, I find, to be mindful that such routines are impermanent, and thus be more than likely subject to change." Although some people might think this would cause unbearable anxiety for the autistic person, I and others (evidently including the author) have found that being aware of the likelihood of changes at some point means less tension and grasping at the routine itself. It's good while you've got it, but you will have to do without it sometime(s). Life will change whatever you do, and acceptance of that is a relief, even to the possibly more rigid Aspie.

I thoroughly enjoyed this book – like the best life changing texts it is short and relatively simple to understand but also densely packed with clear suggestions and observations.

My only criticism would be there is a sometimes narrow interpretation of some of the Buddhist principles looked at and the situations they may apply to, though this is a common style in autie-authored books.

A good follow-on study to this book would be Stephen Bachelor's "Buddhism Without Beliefs".

Possibly to get the most practical effect from this book, it would help to attend some Buddhist or similar teachings for a while. Eckhart Tolle and others have produced large collections of teachings and books on using the mind differently, and "secular Dharma" may be the way forward for Buddhist teachings in a sceptical Western society.

However, I strongly advise avoiding the New Kadampa Tradition (NKT, headed by Geshe Kelsang) and the Friends of the Western Buddhist Order (FWBO, founded by Sangharakshita) as both of these are frequently

listed as cults or distinctly cult-like. Others have different views, of course, but please be careful. Not everything that appears Buddhist is so. You can check out with INFORM if you want to know what people are saying about a New Religious Movement.

NB. INFORM collates information on religious movements.

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Announcement

Dear AU readers

I am writing to let you know that the esteemed John Joyce — the Editor of *Asperger United* — is stepping down from his editorship of the magazine at the end of this year. His last issue as Editor will be the October issue.

Appointed by *Asperger United*'s founder, Pam Yates, John has been Editor of the magazine for an impressive twelve years. During this time his editorials have informed and entertained us, and he has kept a close eye on the content of the magazine.

I would like to take this opportunity to thank John for his hard work, commitment and enthusiasm, and to wish him all the best in his future endeavours. If you would like to thank John personally for his work, please send your greetings via *Asperger United* in the usual way and we will pass them on to him.

I would also like to let you know that the Goth — the NAS contact for *Asperger United*

— has been appointed as the new Editor of the magazine from January 2010. The Goth has been doing a sterling job producing *Asperger United* for nearly four years and I am certain he will make a fine Editor. I wish him all the very best in this new role.

We are currently considering the possibility of making changes to the design of the magazine at some point in the future, no earlier than April 2010. These changes could be, for example, leaving more space and using clearer fonts to make it easier to read, and using colour. Colour has been much in demand and using it would mean we could include coloured artwork and better differentiate sections of the magazine. If you have any strong views on the design of the magazine, please let us know.

With best wishes

Kathryn Quinton

NAS Publications Manager

Autscape 2009: Effective living

West Wickham, Kent, UK

Tuesday 18 August – Friday 21 August

Autscape is a residential conference and retreat organised for, and run by, autistic people. With successful annual events since 2005, this will be the fifth Autscape.

Participants in previous years have come from across the world to discuss issues affecting autistic people and have enjoyed the chance to go to workshops and presentations, and to interact with other autistic people.

Autscape is designed as an autistic-friendly environment. Effort is made to minimise sensory and social stressors, and autistic people are not expected to conform to NT social standards. Non-autistic people are also welcome. All we ask is respect for “autistic

space”, a non-judgmental attitude and an open mind. Registration is due to open in late April and space is limited, so ensure you register promptly.

The call for proposals closes on the first of May. For further information, see the website.

Email: info@autscape.org

Telephone: 07941 343 026

<http://www.autscape.org/>

Write to: Autscape, 4 Falcon Street, London, E13 8DE, United Kingdom.

New NAS service:

Community Care Case Worker

The Autism Helpline now has a Community Care Case Worker who offers a service where advice, information and support can be given about Community Care issues. This includes finding out what help you can get from Social Services (eg. direct payments, day centre and respite care provision, housing options, etc), how to access this help and how to make a complaint to Social Services if you are not happy with their decisions or services.

To use the service, phone the Autism Helpline on **0845 070 4004** (Monday – Friday, 10am – 4pm), where details of the query will be taken and a telephone appointment with the Community Care Case Worker will be arranged. They will then call you back at the agreed time to discuss the issue in detail. Or alternatively you can email your enquiry with as much detail as possible, along with the name of your local authority, to communitycare@nas.org.uk



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