

Produced by and for people who have autism-spectrum conditions

# Asperger *United*

Edition 70 April 2012

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# 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 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. 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 £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

*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.

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

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Tel: 020 7903 3595  
Fax: 020 7833 9666

Email: [asp.utd@nas.org.uk](mailto:asp.utd@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 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 *AU* by **21 May 2012**



**Welcome** to the April edition of your magazine! The previous editor, John, was always keen to thank you for the high standard of submissions; I have wrongly overlooked this until the exceptionally high standard of the postbag this quarter. Thank you to everyone who sent something in; it has been particularly hard to choose the contents this issue, especially as many of the best contributions were quite long. So hard that I've decided to run our first double feature, with articles about the challenges of raising a disabled child and the myths of autism, though you'll have to wait until next time to read the rest of the *Challenges* feature.

This edition is also only the second time I've serialised an article since I took over production of the magazine in 2005; serialisation used to be more common in *Asperger United*, so let me

know what you think of this option. One use of serialisation is to break up long articles into manageable chunks: does anyone feel that the long articles in this edition are too much? Would you like to see them broken up over two or three issues?

And finally, after many years of requests, we have our first puzzle and some humour. I'm eager to know what people think of these, and look forward to more such submissions.

Also, if anyone would like the solution to the puzzle, let me know, as I'm not planning on printing the solution because I think anyone who's interested will be able to solve it, sooner or later, especially if they check the wording of the description (if they're stuck),

the Editor

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## the living edition — double feature! — next issue notice on page 10

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### Contents

Art by Leonie . . . . .	cover
– a double image to suit the double feature	
Feature by Claire . . . . .	4-5
<i>Challenges</i> , part one	
Book review by Walki . . . . .	5
<i>The zombie survival guide</i> by Max Brooks	
Letters in reply to Olly . . . . .	6
from Richard, Nadine and Frances-Mary	
Pen pals . . . . .	7-8
Notice about a new AU email service . . . . .	9
Book review by the Goth . . . . .	9
<i>Business for Aspies</i> by Ashley Stanford	
Letters to the Editor . . . . .	10

<i>Personal grooming</i> – article by Felicity . . . . .	11
<i>Wordsearch</i> – puzzle by Annette . . . . .	11
Feature by Luke Beardon . . . . .	12-13
<i>The myths of Autism</i>	
Letters about Specialisterne Scotland . . . . .	14-15
from Louisa and Specialisterne Scotland	
Adverts for two more groups . . . . .	15
(following on from last issue)	
<i>Uncommon thinking</i> . . . . .	16-17
article by Cara Dovecott	
<i>Freedom Passes</i> – article by Ross . . . . .	18
The rules of <i>Asperger United</i> . . . . .	19
<i>Autscape: an autistic conference</i> . . . . .	back cover
notice from the Autscape organisers	

## Challenges

### part one

by Claire

My son started high school today. Not a fantastic achievement, you'd think, everyone does it . . . but then not everyone is Andrew . . . .

He was born four weeks early. He showed no signs of being early and was a good weight (6lb 6oz). He was a good, happy baby but something wasn't quite right. Of course none listened to me — what could I possibly know? — and nothing was done. "Boys are always lazy" they used to say to me, and "don't worry, he'll catch up." Even at six months old he would be happy to just lie on the floor for hours. His favourite was lying in front of the bookcase, he'd kick his legs and make little noises . . . but that was about it.

Everything changed when he went for his eight-month check. Now, of course, because it was one of "their" "official" check-ups, the results were obviously far more important than anything I'd been saying for months! And all of a sudden it was all "hadn't you noticed x, y or z", "this isn't right", "that isn't right" and accusing stares. Then on top of everything else he went from being a milk addict to completely refusing to drink it and started losing weight.

So, then came about a year of appointments, doctors and hospitals, scans, tests until finally a neurologist figured it out. The problem was he'd been born with two separate and pretty rare conditions. At the time there were no known cases of someone having both and neither had a particularly good outlook. There I was at 18 being told I was going to have a seriously disabled child who would never walk, talk, feed himself, go to school . . . . I've had better days!

But that was it! None offered me any help or information. It was just this is what's wrong, off you go home! Unbelievable! Then we got offered a two-bedroom flat. Great, I thought, but it was on the first floor and when I explained

the situation and that Andrew would be in a wheelchair later, the council said if we didn't take it we'd go to the bottom of the waiting list! "We'll move you later if needed" they say; yeah right. So we took it and I loved that little flat. In many ways I wish we'd never left. You know when a house just has that "home" feeling?

Anyway, I could find hardly any information, even on the Internet. Nothing like now. But I was of the opinion that you can't just give up. Seems that Andrew was with me on that too.

I went back to endless appointments and there were doctors, neurologists, opticians, ophthalmologists, endocrinologists, dietitians, special diets, physiotherapists, exercises, measure this, check that . . . . At the time it felt like not a week went by without something and I had to do his physio twice a day (which I incorporated into getting dressed, as he hated it!) and then seeing a paediatrician once a month. Might be the odd other check up thrown in but at least it was easier. I remember one neurologist, right big-headed git, he was. When I asked him where I could get more information he said, "you can't, I am one of the leading doctors in this field." You have to remember that I looked about 14 and was well aware what people were thinking of me and why these things were wrong with Andrew . . . so when he gave his gloomy predictions for Andrew's life, I told him, "You're wrong, just wait and see." I think that's the point my screw-you, don't-tell-me-what-to-do, I'm-doing-this-and-you'll-see attitude really kicked in. Mr oh-so-clever neurologist had to later admit he had no idea why Andrew was, for want of a better word, normal, because it's never happened before. Apparently his case has been written about in medical journals.

For a long time there were no real problems. He ate and ate but never put on anything, but then he never stayed still either: Andrew was bound



## feature, part one (continued) and a book review

to be tall and skinny. He was on this ridiculously high-calorie diet for a while — I was making his porridge with cream! — but it made no difference, so eventually it was just accepted and left.

Our next problem was school. None of his doctors thought it was a good idea or worth it. They wanted to send him to a school for disabled children, but it wasn't really a school as such. He would have some lessons but nothing major and he wouldn't be pushed, which was good because then he would get disappointed and feel bad when he failed. God, thanks for the vote of confidence there; what do you mean when? Whatever happened to if? Are you not even allowed to try any more? Boy, am I glad I stuck to my guns on this one! Since he started catching up developmentally it was pretty obvious there was nothing wrong with his intelligence at all. If anything he was ahead. Told them that, with or without their approval, he was going to a mainstream school. He did go, he did okay. Would have done much better but the school were absolutely crap with him. He had a lot of behavioural problems. (Later found out he has ADHD, I did most of the work on that too as no one else was interested again, with their who-cares, he's-never-gonna-be-anything-anyway attitude. GRRR.) He's on the Gifted and Talented Children programme, was in the school band (hated it) and school council and continuing to prove medical science very wrong.

He still has problems, his behaviour is an issue, and socially he has real problems with body language, social cues and so on. He also has very little common sense but the boy is so smart. He understands stuff that fuzzlys my brain! He has a maths/science brain and I really don't! Last year I did an Open University course in how drugs work and, after explaining some words he didn't know, he understood it all. He did an old GCSE paper at school and said it was "well easy". At about 7 he was assessed as having a reading age of 11: I don't think I need to worry about his intelligence.

Today he started high school: got him into one of the best in the county.

For a boy who "won't do anything" that's quite an achievement, don't you think?

## The zombie survival guide

by Max Brooks

ISBN: 978 0 71563 318 2 £8.99

Duckworth and Co. Ltd, 2004

review by Walki

I was chatting with a friend one day and asked what interested her so much about zombies. She suggested reading *The zombie survival guide (complete protection from the living dead)*, an intelligent book providing scientific facts, proven means and historical events.

First, Brooks explained that a virus called solanum turns people into the living dead. It is not airborne or waterborne, nor found in vegetation. Humans can be infected through direct contact. The virus needs only twenty-three hours to take effect. It settles in the brain, so destroy the head to dispatch them.

Brooks writes about the do's and don'ts of surviving any outbreak. He gets into details for every possible weapon: knife, gun, hammer, blowtorch, poison, and so on. He studies every terrain, starting with your home. He insists on defence, but also considers offence. If you have to move, Brooks advises you on what to take.

Most importantly, he dedicates a chapter to the class-four outbreak: how to start over in a world taken over by zombies. Key words: prepare yourself, anticipate. You will also have to deal with the hostile living: pirates and bandits. Brooks reckons it would take a minimum of twenty years for zombies to disappear. Brooks also compiled every *recorded* zombie attack since 60,000 BC for any part of the world.

I've read this guide with great interest, as you never know. The author himself "lives in New York City, but is ready to move to a more remote and defensible location at a moment's notice". This book could save your life.



## three letters in reply to Olly, issue 69, and a filler

Hi Olly

I learned to drive through BSM — I didn't see any need to tell the instructor of my diagnosis, and had there been any issues, since BSM is a large network of instructors, it would have been easy to transfer to another BSM instructor. So maybe a large company of driving instructors could be a wise move — there is, of course, also the AA.

I passed my test (at third attempt) in March 2006, and have driven about 75,000 miles since then without any problems, so the mere fact that you have a diagnosis of Asperger's shouldn't stop you. There was a documentary about driving on the spectrum earlier in 2011, in which the driving instructor was on the spectrum herself. Here is a YouTube link to part of that programme, called *Autistic Driving School*:

[www.youtube.com/watch?v=S93scNE94Ho](http://www.youtube.com/watch?v=S93scNE94Ho)

I hope this helps.

Richard

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I am writing in response to a letter from Olly, printed in the January edition. Being parents of a child with Asperger's, myself and my husband along with Julia Malkin ADI MBE have set up a group with the long-term plan of a website and a charity. Aspire 2 drive is currently a new group on Facebook where people can share information regarding any aspects of learning to drive. Julia offers training for driving instructors so that they can correctly teach people with ASD. The aim of our charity will be to provide the funds for ADIs (approved driving instructors) to complete this training so that this specialised teaching is available in more areas. Anyone is welcome to join our group and share stories or information.

Thank you

Nadine

Dear Editor,

I wanted to let you know that I passed my driving test (automatic) just before Christmas, after twenty-one years and seven attempts.

I managed to achieve this with a lovely examiner and booking a double slot for my practical test, which eliminated any pressure and multiple instructions.

My instructor was a young lady I went to primary school with, so she knew me very well. I also drove with my father for a long time, and more recently, my husband. It would largely depend on which area Olly is living regarding a suitable instructor. There is a lady who runs a driving school in Leicester, who has Asperger's syndrome though, and an organisation called the Queen Elizabeth Foundation, which is in outer London, might also be a possibility. They deal with all types of disability, including AS — I had an assessment there some years ago and found them very understanding. They also have a private driving track and cars with adaptations. It sounds as though Olly would be happier in a vehicle with automatic transmission, as there is much less to worry about (no changing gear, for instance). The only thing is that if you pass your test in an automatic, you can only drive an automatic, so do be aware of that factor. Also, don't forget the theory test you can get extra time for that and a separate room if you book in advance.

The DSA Theory and Hazard Perception is worth using.

Yours faithfully,

Frances-Mary

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I used to think that others knew exactly what they were doing and I was somehow the only one who didn't. I now realise they don't either. What's more: they think that I know exactly what I'm doing . . . .

Tom



# Pen pals

## Pen pal number 117

**My name is Kirsty**, I am 21, nearly 22, and diagnosed with autism, dyspraxia and learning disability, along with mental-health problems.

I belong to a nationally recognized choir called Rock Choir. I am obsessed with dolphins and I like fashion. I am also writing a book about my life with autism called *A day in the life of an autistic girl*. I love computers also.

I live in supported housing, but want to move away from this town so that I feel safe away from people that have bullied and abused me — I wondered if anyone knew how it is possible to move; do I need to get special permission from social services?

Some of you may know me from the *Autistic me* documentary, but I have changed quite a bit since then and have come out — I prefer to say I am attracted to women rather than define me in a category, but I belong to a LGBT (Lesbian, Gay, Bisexual and Transgender) group which I find difficult to mix in with other people who are neurotypical — although I try, it's difficult. I have a few friends, but one particular person is teasing me because I like dolphins, which means that he can say he is going to eat a dolphin which upsets me. But I have friends who turn around telling the person that he couldn't because they are far more intelligent than he is. Although I attend, I try to socialize, but it's quite difficult; I am just sat there really quiet until someone comes up to me and talks. If they ask how I am, I say, "I am okay" but then don't say anything else after unless they ask a question.

## 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](mailto:asp.utd@nas.org.uk)
- > We will pass your letter on to the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.
- > Please note that all pen-pal letters sent via *Asperger United* are opened before being passed on.

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

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

### Pen pal number 118

**Hi, I'm Alex** and I'm a 29-year-old man. I diagnosed myself with Asperger's about twelve years ago and thought it about time to share life experiences with other people. I work full-time and never go out socialising so have no real friends. My main interests are the history of passenger ships, military history, filmmaking and screenwriting which I like to do myself. I'm interested in meeting anyone who likes to be creative in some way. I prefer to email as it's so much easier. Many thanks.

---

### Pen pal number 119

**My name is Kereena.** I live in the Midlands area. I am 41 years old. Last year I was diagnosed with Asperger's syndrome.

My interests are going to church, listening to music, playing lots of instruments — brass best — can learn to play a new one in less than two weeks — that is my gift. I only got one friend I see and helps me out and she is NT. I am looking for someone around my age or over 18. I am a parent with children. I live alone. And ladies only please to write, or even another parent or a family to write to, please, or at least a mum who has a husband that is on the spectrum who can relate to me. My children are 23, left home, and 10 and 12 at home.

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### Pen pal number 120

**My name is Chris,** I'm 33 years old. I was born in Hemel Hempstead and I live in Welwyn Garden City. I was raised in Singapore. If any others of you went to international school or studied abroad I would love to get to know you. I like singing and dancing and travelling. I got diagnosed with Asperger's on my twenty-first birthday. To those of you who went to international school, I'll look forward to have group meetings.

### Pen pal number 121

**Hi, my name is Cass.** I am 21 and was only diagnosed with Asperger's a couple of years ago, despite always having problems. I also suffer from depression and general anxiety. My main interests are art and my animals; I have two guinea pigs, two rats, two degus and a dog. I guess I'm looking to talk to someone around my own age (but that's not important) who shares my interests and can understand me and how I'm feeling as I struggle keeping friends because of the way I am.

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### Pen pal number 122

**Hi, my name is Shane,**

I was diagnosed with Asperger's when I was 10. I am 12. I like playing on my Xbox 360 and my Wii. I mostly like playing with my Lego. Ever since I was 3 I loved Lego. I have good art skills and cooking. I like to listen to music (rock, jazz, anything). My best TV shows are *Waterloo Road*, *EastEnders*, *Corrie*. My best-ever movie I watched is *2012*.

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### Pen pal number 123

**Hi, my name is Adam.**

I am 11 years old and live in Warwickshire. I was diagnosed with Asperger's syndrome just over a year ago.

I am mad on computers and really enjoy playing games on them. I also like going to the cinema and swimming.

I find it hard to make friends and would love to become pen pals or e-mail pals with similar children.

Hope to hear from you soon.

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*Five pen-pal adverts have been held over for next issue.*



## Making it easier to read *AU* in the digital age

Those of you who read *Asperger United* on line have been asking for email notification of when the new issue will be on the NAS website. Well at long last email notification is on its way.

Please be assured that the paper version will continue: email notification is an extra service and I am well aware that most readers have no computer access.

*AU* will have access to the technology to send email notifications within the next year. Email notification could work in two ways: either the email would contain a link for downloading the electronic version or the email would have *AU* as an attachment. When the notification system is ready I will make an announcement in *AU*. Anyone wanting email notification will be able to sign up on the NAS website or send in the form which will be sent with *AU* when the notification system is ready.

Everyone is welcome to receive both the electronic and the paper versions if they want.

Many people have been asking for email notification for years, so I want to know how people feel about it now. Let me know if you would prefer a link or an attachment. I shall look forward to your letters (including emails!) on this and other subjects,

the Editor

## Business for Aspies

forty-two best practices for using Asperger  
syndrome traits at work successfully

by **Ashley Stanford**

ISBN: 978 1 84905 845 2 £13.99 / \$19.95

Jessica Kingsley Publishers

review by the Goth

Stanford takes everything she's learnt about employing people with Asperger's and living with her own Asperger's husband, and the problems he brings home from work, so it's very much tried-and-tested advice that she's put into practice herself.

Slightly confusingly, she often mentions how the book is structured in three parts and makes references to these parts, but the book is structured in chapters, just like most books, though including two chapters "thirteen"!

Nevertheless, this is a very useful book, even for people who have no intention of working, or for partners of people on the spectrum, as there is a wealth of details and

anecdotes showing how potentially difficult situations can be dealt with, both at work and at home. More has been packed into these 230 pages than into many other, longer books. Some of the best practices, of course, will be too difficult to achieve: myself, I can't manage the "quiet" body posture she recommends, but the book is worthwhile despite this. As well as the forty-two best practices, these practices are put in context, and after them are ten "survival" strategies, most of which apply to life, not just work.

I think this is a very useful book for employees, employers, colleagues and support workers. I expect everyone will find something new here.

*This book is available from all good bookshops and through Amazon's charitable scheme at*

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

*and if you use this address instead of the usual Amazon one, the NAS gets a donation from Amazon.*

## letters to the Editor and a notice

Dear Goth,

yet again many thanks for another superb edition of *Asperger United*. I received my copy of edition 69 on Christmas Eve, and I am replying on the day after Boxing Day. I hope your Christmas was good, and that the new year will serve you well.

I want to respond to some of the articles in edition 69. As a lone man aged 62, with three offspring around the age of 30, and two very young grandchildren, I feel that I fall somewhere in between the experiences of Aida and Robert.

All three of my "children", and also their mother, show signs of the damage which I have caused, but, whilst none of them are particularly settled, they are all reasonably successful in their lives so far. It is hard to know whether the damage was caused by my behaviour over the years, or whether I passed it on in my genes. My feelings of guilt and remorse are always greatest at Christmas-time, but one thing we are all agreed upon is that, like Aida and her dad, together we saw the sea, the mountains, the skies above and the winds between and the benefits of those experiences will remain with us forever. My wife and I were together for thirty-five years, and although we now live apart, we remain inseparable.

The various articles and poems in edition 69 highlight, as usual, the difficulty of "pinning down" the different individual experiences of AS — many sufferers are seriously disabled by the physical symptoms of AS, whereas others seem to be able to manage an outwardly normal existence whilst struggling inwardly with their social inadequacies. I find these variations confusing, and hard to explain to others,

Kevin

If sufficient material is sent in, the theme for July will be **creativity**. All creative expression: art, writing, singing, music, problem-solving, . 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!

## Living

For years I lived in Wales with my mother and I could not go anywhere without her — not because I needed her to be there but because I didn't know any different. Before I was diagnosed as Asperger's, I was escorted everywhere anyway because I was a child.

As I got older I wanted more freedom but outside the house, I wasn't going to get that, so every holiday that came along, I went out when my mum and stepdad were at work and I returned before they did. I did this until I moved back to Preston.

Also the only activities I did were line dancing and Girl Guides.

In 2006 I moved to Preston and started a new life — a life full of freedom. I did things I never got to do in Wales! It didn't happen straight away, but over a few months I went shopping on my own, I went to parties and pubs and nightclubs. I don't go out that often to pubs and clubs but my schedule is hectic anyway:

Monday: Guides; Tuesday: women's bible study and dancing; Wednesday: work and Good News group; Thursday: slimming; Friday: Rainbows; Saturday: day off; Sunday: church. Also I have to do my chores. I do eat, drink and sleep in between! I cook frequently with my stepmum and if I can I have a lazy day in my pjs.

I proved to my mum last year I could travel alone with no problem and two years ago I proved it to my grandparents and those are achievements that I am proud of and my grandad stopped making suggestions on how to get to them that would cost more than I was willing to pay.

This part of my life is to be continued when I live on my own.

Cristina



## Personal grooming: what a fiasco!

by Felicity

I wouldn't say I had many joys with daily grooming, but I've overcome some of them Aspie-style.

I find styling my hair impossible because I get confused by mirror symmetry. It would be so much better if I could screw my head off, sit it upon a table and style it from all sides using a spare set of eyes in my neck. Unfortunately for me, evolution has not progressed to that stage yet!

To overcome my "hair wars", I drag a detangling comb through it after washing and scrunch it with my fingertips to try and accentuate its natural waves. Though when it's dried it often has this habit of looking like a bird's nest (minus the birds).

I cannot tolerate the texture of hair wax or hair gel even. The smell of hairspray makes me gag. I sometimes, though very rarely, use a little bit of hair mousse but this has a habit of making my scalp itch. Conditioner has this effect also. So, to make my "bird's nest" soft and shiny, I wash my hair with a famous brand of baby shampoo. No conditioner needed!

Make-up is another source of pain and confusion. I often go without, but I quite like to wear it for a night out. On those occasions I use a very light foundation. Even though this foundation claims to be "soft and light-feeling on the skin" every cell on my face is irritatingly aware of its existence until it's washed off.

Eyeshadows are an enigma in themselves. I used to wear an array of garish shades and colours around my eyes as I could never decide which ones to use. This stopped when peals of laughter from passing girl gangs translated inside my head as "You look absolutely ridiculous!"

Now I just use a coat of black mascara on my lashes to "bring the eyes out". Job done.

Blusher is rationed to a light sweeping of cerise or soft red rouge on the cheeks. Don't overdo it though ladies! I spent years looking terribly embarrassed (and enduring more peals of laughter). Less is more! For my lips, I use a lip tint. I find it easier to use than smothering my smackers with a waxy substance, also known as lipstick.

And there goes another example of my tactile hatred of waxy textures. Lip gloss can also be added to that list. The best thing about lip tints is that they give lips that "bruised berry" look and don't leave a mark on your favourite mug (or anyone else's).

On a final note, bras cause the most tactile annoyance. I gave up wearing bras a while back and now wear soft, stretchy cropped vest tops. They don't always stop things from "heading south" but they sure are comfortable with no hidden wiry surprises to dig into my poor, suffering flesh.

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### Wordsearch by Annette

The words "Kanner", "autism", "Asperger" and "high" are hidden four times each in the grid. There are two extra hidden words which appear once each. Can you find them?

The words snake around. All letters are used only once; an example is given.

KANNEUTERHNI  
ATUARAIGGIET  
SISMRSRHKOU  
PAKGEGMENARR  
ENRRHISPNEGE  
RNEEMCTSARRE  
GESPSAKAUHGP  
HRAAIFANTMIS  
IGHUTRENISHA

## The myths of autism

by Luke Beardon

Author's note: by writing "autism" I am including Asperger syndrome; read on to find out why.

Author's note number two: I am writing about autism; I am categorically not writing about people who have both autism and learning disabilities.

Author's note number three: if anything upsets you while reading this, please accept my apologies. All this is simply my opinion — open to question, absolutely. Nothing written here is intended to offend anyone.

This article is not (necessarily) fact. I do not claim to know all there is to know about autism; indeed, all I can claim is that I have a very keen interest in autistic people and have been working in "the field" for twenty years or so. I probably know a bit more than the "average man/woman on the street" but am more than happy to embrace the notion that in light of what there is yet to learn, I remain pretty ignorant. The main point of this article is to try and highlight all the so called "facts" that are peddled about autism which lead to ignorance and misunderstanding; my intention is to question the building blocks upon which many professionals have based their knowledge, to create fissures in the foundations, and

to urge the professional sector, simply, to think again.

I am somewhat constrained by a word limit; well, that and the fact that I want to keep some of the detail to include in a publishable book, so I am not going into as much detail as I could. If you're a professional reading this and getting all indignant that I am suggesting that you are not as clued up as you should be, then you're probably one of the good ones.

**Myth: autism is a mental illness and/or a disease.** Okay, now I am not suggesting that in modern times people are still suggesting that autism is a mental illness or a disease (please don't tell me if they are, there's only so much ignorance a person can take). *But:* if this is the case, why are sets of criteria to be found in the International Classification of *Diseases* and in the tome published by the American *Psychiatric* Association. Why do people often get referred to a *psychiatrist* for a diagnosis, why are children often referred to Child and Adolescent *Mental Health* Services (when there are no mental health issues evident)? I am not suggesting for one moment that there are not good psychiatrists or mental-health professionals out there, but what "qualifies" them to work with autistic folk? Surely, the erroneous connotations twixt

autism and mental illness/disease are not safe, nor sensible.

**Myth: Asperger syndrome is mild autism.** Excuse me for while I grind my teeth and bang my head against this convenient wall. Just don't go there — ever. Just because someone is articulate, intelligent, amusing, fun to be with, interesting, loyal, fervently determined to right the wrongs of the world does not mean that they are "mild" anything. (In fact, that list could be the beginnings of the new set of diagnostic criteria for AS). People are either autistic or they are not. The severity (that is, the impact on the individual) will vary, dependent on numerous factors. So-called "severely autistic" individuals may be supremely happy; so-called "mildly autistic" individuals may be suicidal; you do the maths.

**Myth: autism consists of a triad of impairments.** No, it doesn't. There are clear differences between the development of the autistic child and the predominant neurotype (PNT). Difference does not equal impairment. A different way of developing does not automatically mean the individual is impaired. Even if one might argue that a certain "skill" is lacking, does that mean that the individual should be branded inferior? The PNT have the "skill" of chatting at



length about essentially nothing: quite the coup, perhaps, but is it sensible? Many autistic people have the “skill” of chatting at length about subjects that are important to them: neither group is “right” or “wrong”, they simply possess different skills. Professionals must stop this branding of autistic people as impaired, deficient, or inferior, as it’s simply not true. Of course many people face problems; those problems are a combination of the individual plus the environment — not simply the autism. In this case, surely the sensible way forward is to change the environment, rather than somehow trying to change a person’s autism (which ain’t ever gonna happen).

**Myth: autistic people are not sociable.** Where did this bizarre and incalculably inaccurate notion come from? Some people with autism will happily while away their lives with no interest in others, and this should be perfectly acceptable (note: if a person genuinely does not want to engage socially, don’t force them to; it can be tantamount to bullying). However, others might be hugely sociable, seeking company left, right, and centre. I suspect the PNT population is pretty similar. Sociability has nothing to do with whether someone is autistic.

**Myth: AS is an intelligent form of autism.** Yes, people with AS have average or above average intelligence. But, since when did autism denote intellectual impairment? If this was the case then surely

the notion of “co-morbidity” with a learning disability would be defunct? (I am deliberately using “learning disability” here to denote intellectual impairment; as opposed to “learning difficulty”, such as dyslexia, which has nothing to do with intelligence). As far as I am aware, being autistic does not equate to being intellectually impaired, so the distinction between autism and AS can be questioned. Unfortunately, it appears that some diagnosticians make the assumption that the diagnosis of autism implies intellectual impairment; in isolation this is not accurate.

If one (rightly, in my opinion) recognises that all autistic people are very much individuals, then such sub-classifications become highly questionable. What’s wrong with simply identifying the individual as autistic, and leaving it at that? As a brief aside, is there anything more ludicrous than the notion of “atypical autism”: if it wasn’t so tragic it would be laughable.

Some other myths that clearly speak for themselves. Autistic people:

Can’t look you in the eye

Can’t have a relationship

Won’t ever work

Don’t make excellent friends

Will never be independent

Are no good at sports

Can’t be good leaders

Never show their emotions

Are unfeeling and cold.

The above are so obviously insanely ridiculous I shall not waste any more words expanding on them.

There is nothing that an autistic person cannot achieve in life as a result of being autistic. All sorts of other things will come into play, of course, but autism alone is not a barrier to anything. Those professionals who turn into soothsayers for parents, and who predict doom and gloom at every turn should be ashamed. They are not fortune-tellers, and there is no way of knowing at childhood what the future holds. Yes, life is considerably tougher for most autistic people than their PNT peers, but it does not mean that dreams cannot be achieved.

I’ve merely skimmed the surface of the sea of ignorance that is evident “out there”; by no means am I suggesting that all, or even most, clinicians and professionals are ignorant to a significant degree. However, I would stand by the sentiment that there is enough ignorance in enough clinicians and professionals for there to be a significant and negative impact on the lives of people with autism and their families. Clearly, this is unacceptable. Until it is accepted that the autistic population is not one to fear, to marginalise, to brand inferior, or to decry as impaired, it seems obvious that there is still work to be done. Such ignorance is neither an excuse, nor is it in any way, bliss.

## Response to Chen's article in edition 69

### Are Specialisterne all they're cracked up to be?

Chen mentions a presentation about Specialisterne Scotland at the Autscope conference. I would have quite liked to have put a few questions to Alastair Cooper (the speaker) if I'd been there myself.

When I lost my job in May 2009, more than one person emailed me news stories about this amazing new enlightened software firm from Denmark who only employed people on the autistic spectrum, as Specialisterne tended to be described. At that time Specialisterne had yet to open an office in the UK, and as I don't speak Danish nor have any yearning to learn it, emigrating to Copenhagen wasn't an option. I did manage to email Thorkil Sonne (the company's founder) partly in the hope that I might be notified as and when Specialisterne did open a British office. Admittedly, I had my reservations as to how suitable the work would be for me, as the way it was described in the various newspaper articles I'd seen made it sound rather dull and repetitive. Personally I regard computers as a means to an end, not the most interesting thing in and of themselves.

However, in the event I found another job through the open market in June 2010. Unfortunately that didn't last, and I found myself signing on again in December. By then Specialisterne had opened their first UK office, in Glasgow; I think this may have been in November 2010, although I wasn't informed at the time. I bookmarked Specialisterne Scotland's website, but it wasn't until August 2011 that they advertised for new recruits. I had a go on their online application form, which to my eyes had a rather odd layout. With regard to job titles, I was presented with a choice between "software tester", "business analyst", "web designer" or "trainee/volunteer", but I couldn't find any actual job descriptions anywhere on the site. Also, there was only space to include one university degree and one previous job. Rather out of keeping with a company whose slogan is "passion for details"! On further

investigation I found that when I hovered the mouse over "Applying for..." I got "Candidates with an ASD should select the Trainee/Volunteer section". Coincidentally I happened to meet (in the virtual sense) a Specialisterne Scotland employee on an Asperger forum, and she explained to me that Specialisterne Scotland only pay travelling expenses to trainees, not full salaries — hence the use of the word "volunteer". This being the case, I didn't see any point in progressing my application further, as I was living in London and couldn't have afforded to move to Glasgow for an unpaid position. It is very strange that Specialisterne don't make this clear on their website.

#### Louisa

*Asperger United offered the right of reply to Specialisterne Scotland. The General Manager's response to Louisa is below.*

*I contacted Specialisterne using the "general" response form on their website. This was treated as a request for their testing services and forwarded to their e-Business Manager, whom their General Manager described as being off work for "the last few weeks". This explains why he wasn't answering his phone, but fails to explain why Specialisterne hadn't been answering his phone and email for so long.*

*Unfortunately, the response doesn't explicitly address the points Louisa makes — which would have been more helpful — and the apology is buried in the middle of the letter. I sincerely hope they learn from this.*

*By being persistent, I eventually got the following response:*

**I am the new General Manager at Specialisterne Scotland, having joined in October 2011.**



## a letter (continued) and two social group adverts

Our strategy is to aid and support people on the autistic spectrum into work. We focus on the IT sector, specifically software testing for corporate clients in the UK. Software testing is a vital part of the software development process ensuring that web sites, systems and applications are fit for purpose and meet the needs of the business. We have also done some web site development for local authorities and third sector organisations.

A majority of our employees have a diagnosis of ASD, my management team includes two autism support professionals with several years of experience training, assessing and working with people on the autistic spectrum. We launched in August of 2009 and had around 150 applications of which twelve resulted in selection for our comprehensive IT training and assessment programme. Please accept my apologies if the online application website wasn't perfect, we are constantly improving our websites and systems and will take your comments on board.

The job titles of web designer, software tester are fairly standard job titles within the IT world however I will look at expanding these explanations on the site. We will make it clear in future that the jobs are based in Glasgow, however we may eventually find clients anywhere in the UK and so some employees may be required to travel.

Some of the trainees can expect to join us as permanent employees and others may be offered an associate contract. A few may decide that software testing and web development isn't for them and we always try to help these people with other choices. The second group is currently taking their software testing foundation examinations and the next opportunity to join this programme is likely to be announced in the summer of 2012. Our new website will be released in good time to provide details of the opportunities at Specialisterne Scotland in 2012.

**Stephen Allott**  
General Manager  
Specialisterne Scotland

## More social groups

Anyone who is the Maesteg and Bridgend area who is over 18, with Asperger's or on the autism spectrum. If so please contact me, **Kim Morris**, on

**07974 630 335**

**kim.morris67@yahoo.co.uk**

so that we can get together and support each other.

---

We are **Asperger's Youth Club** and we run in term time only between 5.30 and 7pm, at Intake in Doncaster.

We welcome young persons from 8 years upwards — but are not able to start anyone new from the age of 21.

We do not tell any members that they are too old to attend when they get to 21, as they decide themselves when they do not wish to attend.

We are just a social group — mainly there for help with the social skills — sit and have a chat with one another or play DSs together.

We have a Wii, table football, pool, table tennis. We do some sort of cookery/bakery every month.

Membership is £5 for the year and 50p each week on the door, there is a tuck shop with very reasonable prices.

For any further information email

**aycforyou@gmail.com**

Thank you

**Karena**

*Postal responses to these adverts can be sent via Asperger United, Ed.*



## Uncommon thinking

by Cara Dovecott

In this edition of *Asperger United* we're myth-busting. There's a mean side of my character that would like to tell people that I have lined up the contents of my kitchen cupboards in alphabetical order and then shout "April fool", so I can watch to see whether the comment on the cupboards or the fact I was joking was what people believed. A fog of misconceptions about autism gets in the way of me relating to people. Ah yes, relationships, that old chestnut. *AU* kicked off the new year by dedicating its first edition of 2012 to the biggest issue of them all. (No, not the crowds that may or may not descend upon us for the Queen's Diamond Jubilee; and then again for the Olympics; and if that wasn't enough there will probably be yet more crowds at the mass celebrations that are being planned as the National Autistic Society chooses this of all years for 50th anniversary celebrations — stop it everyone I hate parties.) No, for me, there is no issue bigger than relationships. In the years both before and after my autism diagnosis, at the age of 32, I struggled to get on with: family members, neighbours, and colleagues, and I have faced difficulties both making and keeping friends and finding a partner. I'm 40 this year (sit down before reading this it may shock you, no I will not be having a big party), and eight years after being diagnosed I'm still struggling with relationships. No other issue has been the cause of more anxiety in my life than relationships. Judging by the comments in January's *AU*, relationships are something we all feel frustrated by, resolve to do differently, and yet struggle with over and over again. I often find myself lagging behind in conversations where I need to find ways of making people who are not autistic — and who presumably have better social skills than I do — feel comfortable with me, so I can just be myself. I usually think of what I need to say when the topic of conversation has changed and the right moment to say something has passed. But with *Asperger United* readers I am among friends, so I had better keep alive my New Year's

resolution, which is to be more real when talking about myself, even when this is unconventional, and start my relationship with you by telling you who I am. I am the Shadow Queen. Opting for the power rather than the parties, I adopted this title at the start of 2012, in order to comment on life as I see it (and it doesn't hurt that at a time when disability benefits are being squeezed the role offers me the chance to state my views with better job security than could ever be enjoyed by members of the shadow cabinet).

My first duty of the year was the awarding of New Year's Honours. As I work towards my resolution to be more real, I honour the gay community. I've dubbed them WBE (We're Bloody Equal/Warriors of the British Empire — delete as desired) in recognition of the inspiration gay people offer me as I talk about who I am, in my relationships day by day. I think my experience of being autistic today is like the experience gay people had back in the 1980s, when, as a teenager, I became politically aware. Autism is still very misunderstood, as being gay used to be. What gay people faced then, autistic people face now. Then psychotherapists tried to cure people of being gay, seeing sexuality as determined by childhood experience, and being over-ambitious in what they could change, psychotherapists gave gay people inappropriate treatment. There are still mental-health professionals, in the UK, who think autism is a form of psychosis caused by childhood experience, which they try to treat with psychotherapy. This is despite the well-publicised research into genetic causes for autism. The prejudice faced by both gay and autistic people is the same, if one's way of relating to others is different, society will see one as broken. If it isn't one's nurture that's at fault, it's one's nature. Then being gay was seen as unnatural. Now geneticists look for a cure for "autistic disorders". Being gay and being autistic are both hidden issues where one's very self is deemed unacceptable and one wonders



how safe it is to tell people who one is. Knowing that gay people have overcome this prejudice helps me talk about who I am as an autistic woman.

Focusing on relationships, again as I look at the gay community I have a sense of déjà vu; the issues are all very familiar. Like us, gay people experience difficult family relationships. They might have parents who reject them because of their sexuality. Likewise, autistic people may have parents who wish they were “normal”. Both gay and autistic people may not fit into our society’s conventions for adult relationships and being parents. Becoming a parent is not straightforward when one is gay and the families created by gay people are atypical. Similarly, autistic people will parent differently and form unusual families — an important issue which I am pleased is being covered in this quarter’s *Asperger United*. Having children is not straightforward, when one is aware of the implications of passing on autism to one’s children and of coping with bringing up children who are different. For both gay and autistic people, issues with one’s parents may mean the support of grandparents is not available to one’s children. There are other difficulties for the millions of people in both communities who do not have children, and so do not fit into society in so many ways: having the same lifestyle as others one’s age, developing social support networks, buying life insurance, to name a few.

In terms of my most personal relationships, the match with the experience of the gay community is there again. As an autistic woman I have had to defend my sexuality. With Simon Baron-Cohen describing autism as the extreme male brain I have had to explain to an ex-boyfriend that I was a real woman not an honorary man. (Her Modesty was not amused.) And yet I am not a typical woman, not able to guess how others feel and offer comfort, not able to read other women’s competitive posturing and subtly standing up for myself with a well aimed comment or gesture. So what kind of woman am I? How can I be straight-talking and feminine? I wonder if a gay man at a stag night feels like a misfit the way I do when surrounded by other women bonding over gossip.

In his book, *The complete guide to Asperger’s syndrome*, Tony Attwood observes that a higher number of autistic people are gay than in the general population. He suggests that because autistic people may not behave typically for their sex, many adopt gay sexuality. I would be interested in hearing the views of gay or bi-sexual readers of *Asperger United*. I wonder whether anyone agrees that their autism has led to their sexuality.

Whatever leads autistic people to their sexuality, I imagine that both being autistic and having a minority sexuality is a complex experience, because communicating with others is necessary to express one’s sexuality. Yet I have heard little about the relationships of autistic people with minority sexualities. For me, flirting, where double meanings abound, is the most mysterious of all neurotypical behaviour. With the gay community having its own social code, I wonder how welcoming it is to autistic people who might not have covered gay flirting in any social skills workshops to which they have had access. I also wonder whether support services for autistic people are relevant to people with minority sexualities. I would be interested in hearing from gay and bi-sexual readers of *Asperger United* who have found, or tried to find, a place in the gay community. I’d also like to hear from gay or bisexual readers about using support services for autistic people. There’s a lot that as a straight woman I can only guess at. Let’s face it; I’m only ever going to be a shadow queen. What I’d like to do is use the views sent in to write an article for the summer edition of *Asperger United* about being autistic and gay/bisexual. A small beginning I know as I’m sure a whole edition of *Asperger United* could be filled with busting the myths of autistic sexuality. Any views sent in will be treated in confidence. Please send your comments to Cara Dovecott at [Word.Heard@hotmail.co.uk](mailto:Word.Heard@hotmail.co.uk) or via AU at [asp.utd@nas.org.uk](mailto:asp.utd@nas.org.uk)

I wait to hear from you as an autistic woman who has borrowed gay culture to talk about being autistic. I talk about “coming out” when I tell people about being autistic, again and again I resolve to make no apology for who I am. This year I’m being bolder: my personal, crowd-less revolution.



## Freedom Passes

by Ross

I have always struggled to tell the difference between left and right, been unable to catch a ball, and, unless I take it very slowly, I struggle to navigate a room without stumbling and walking into something or someone!

An outer observer might draw the conclusion that I am simply clumsy — and I wish it was as simple as that but it sadly is not.

My impaired coordination is a direct manifestation of my dyspraxia as well as AS; both somewhat hidden disabilities which lie within the autistic spectrum. I consider myself very fortunate to work in a role that utilises the positive aspects my disabilities bring, such as an ability to pay close attention to detail and identify errors, along with ICT skills.

However this is me trying to look on the bright side because my life has been full of struggles for me due to disabilities, for instance because of the problems of dyspraxia I knew early on that the concept of driving a car would be very problematic and likely dangerous to myself and other users of the road.

Struggling to comprehend turning left or right, remembering which controls did what, not being able to judge the distance or speed of other cars! And

likely getting overwhelmed from the road noise and flashing lights.

All that if I even got as far as obtaining a licence — which seemed unlikely going on how I struggled to even use a bumper car!

I resigned myself to a life of only travelling when necessary, using the ever growing expense of public transport (which I don't think you even need a disability to get confused with the zones and different types of tickets!).

However, all this changed thanks to the head of the neuro-diverse staff association at work, who told me how she has dyspraxia and was not able to drive herself as a result, so had been successful in obtaining a Disability Freedom Pass which is paid for by your local London borough council and allows free travel on tubes/buses at any time, and on the trains in zones 1-6 past 9:30 am and any time on weekends.

She informed me about downloading the form from my local authority website and how I would need my doctor's support to verify the severity of the condition because just having the condition will not automatically qualify you.

Within a few days I had discussed it with my doctor,

who agreed due to my disability I would not be able hold a licence, so created a letter to this effect which I submitted alongside my application which was not complicated to fill in.

Within a week I received notification it was being considered and around three weeks later received a letter of confirmation with a form to take to a post office alongside a passport photo and two pieces of ID. Just over two weeks later I received my functioning Freedom Pass which I could use with immediate effect.

It has made my life so much easier and has saved me an absolute fortune on travel fares, it truly is a freedom pass as I am more inclined to use it to go places on weekends now as have become more confident in using the tube and train systems. (The fact I no longer have to worry about which ticket I get is also a huge advantage!)

I implore anyone who has a severe coordination disability, as people on the autism spectrum often do, which prevents you from being able to drive *and* your doctor can confirm, to apply for a Freedom Pass — it makes a world of difference.

*For people who don't live in London, a disability bus pass is available from your local authority, Ed.*



## 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 cover 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) 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.
- 3) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- 4) *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.
- 5) If you move house, please inform *Asperger United* and include your old address as well as your new address.
- 6) 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.
- 7) If you want to unsubscribe, inform *Asperger United* and include your address.
- 8) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address.
- 9) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as sometimes 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 you in our records.
- 10) The current edition of *AU* is available at [www.autism.org.uk/aspergerunited](http://www.autism.org.uk/aspergerunited) You need to scroll down to near the bottom of the page, where there is a link to the PDF.
- 11) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 12) 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.
- 13) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.



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

Belsey Bridge Conference Centre, Ditchingham, East Anglia

Monday 23 July – Thursday 26 July 2012

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

Registration is expected to open in April and will close 30 June.

This year's theme is *Similarities and diversities*.

Information, communication and registration:

- Autistic-friendly environment
- Meet others with autism (including Asperger's)
- Non-autistics also welcome
- Workshops, presentations and leisure activities
- Comfortable and quiet location with plenty of outdoor space
- Childcare available
- Affordable registration fee includes accommodation and full-board catering.

Website: [www.autscape.org](http://www.autscape.org)

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

Post:       Autscape  
              24 Anson Road  
              Upper Cambourne  
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              CB23 6DQ  
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The Autscape Organisation.  
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