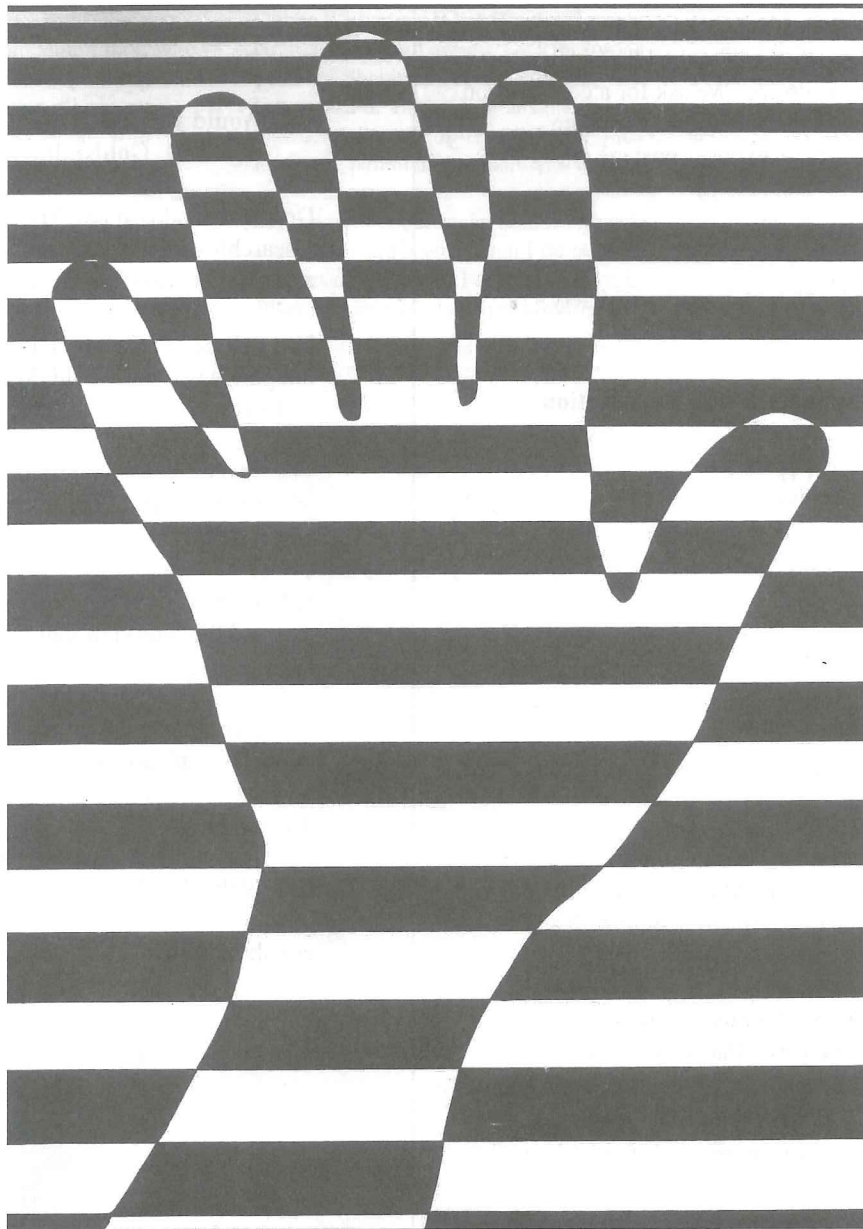


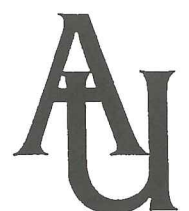
Produced by and for people with Asperger syndrome

# *united* Asperger

Edition **33** January 2003



*'Hand' by Peter Myers*





*Asperger United* is a self-help newsletter run by and for people with Asperger syndrome. The newsletter aims to put people with the condition in touch with each other and to share information so that they can lead more independent lives.

*Asperger United* is free to people in the UK with a diagnosis of Asperger syndrome. We ask for a contribution of £6 per year from overseas readers and £10 from professionals and institutions to cover postage costs.

**Editor** John Joyce

**Additional support** The National Autistic Society's Publications Department

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All we need is your name and address and we will add you to the mailing list – free of charge to people with a diagnosis!

Thank you to George Cox who kindly produced the illustrations included in the Pen Pal Network section.  
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.*

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### **Would you like to help with Research at Goldsmith College?**

Dr Lorna Goddard and Ms Trishna Patel are researching memory from past experiences in adults (aged 18-35) with Asperger syndrome.

You will be asked to recall memories and to imagine what you would do in various problematic situations.

The interview lasts approximately one hour and a fee of £10 (+ travel expenses) is paid for participation.

Alternatively the research assistant could come to you and the interview can take place in your own home.

If you are interested in taking part or would like to know more please contact: -

Trishna on:

020 7919 7388/7175

email: pss0tp@gold.ac.uk

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Dear Readers

Welcome to your first *AU* of 2003. Hope you had a wonderful Christmas.

Before going into your editor's recent activities may I thank all contributors to this and previous editions and invite others to share their writing talents with us.

The major item of interest for the past three months has been the World Autism Congress in November in Melbourne, Australia. Apart from your editor, who appropriately batted last in his session, many speakers dwelt on all aspects of care and treatment of persons with autism. The title was 'Unity through Diversity' and this was expressed in the diversity and unity of the programme, even though Harold Stone, one of the earlier speakers in the session, thought otherwise and expressed his opinion most

vehemently.

The conference was opened by Governor of Victoria and former Olympic track medallist, John Landy and 10-year-old Max Williams, and we were welcomed to the congress by The President of World Autism Organisation, Pat Matthews and Dr Lawrence Bartak.

Speakers included Dr Tony Attwood, Donna Williams, Dr Pat Howlin, Temple Grandin, Wendy Lawson, Dr Rita Jordan and Paul Shattock. Though you may not have heard of all these names they represent all areas of the spectrum: professional, parent and person with autism.

My talk was about social skills. This was a long talk and even though I do not have the best of memories I did not take many notes. There was also an exhibition of

artwork mainly by Australian children.

In addition to the Congress I spent a holiday in Australia - part of it arranged by the conference hosts. This took a few of the delegates to the Blue Mountains about 40 miles north of Sydney, and to Jervis Bay, a similar distance to the south of the same city, to watch dolphins. And in first place, chronologically, a cruise around Sydney Harbour.

In all of these we were given information by our guides on the history and geography. I then spent ten days visiting Sydney and Perth on a private visit.

A report on the Congress will appear in a future issue.

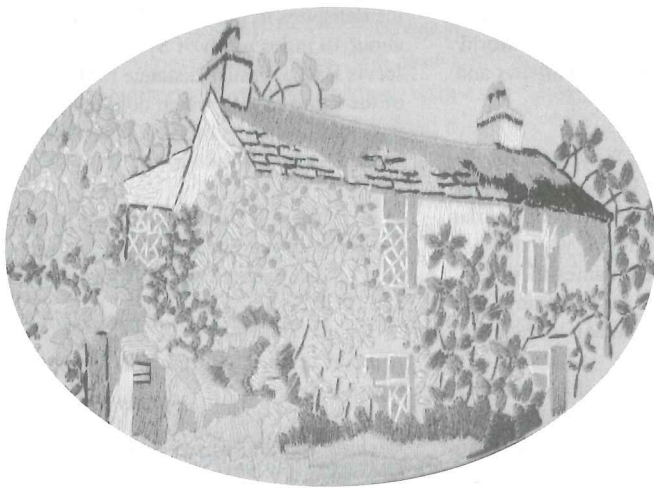
Wishing you all a happy and peaceful new year - John Joyce, Editor



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The cover of our last issue of AU (32) showed a picture of a needlepoint entitled 'Dove Cottage' that was hand stitched by one of our readers, Julie Norman. Julie, who has high functioning autism, spends a lot of her time doing various needle crafts and artwork – she finds it both therapeutic and calming. Here she tells AU the story behind Dove Cottage...



### Dove Cottage

A place surrounded by mystery and thoughts of peace and comfort which is very useful when I feel stressed.

The picture shows different shades of green with its leaves surrounding the cottage. This gives me thoughts of the mystery of what the cottage is really like. A garden gate through which I can enter and see the mystery behind the windows – I see through the eyes of my autism.

The cottage sends me a message of what life is really about. I feel at peace in this cottage. I imagine the people who live in the cottage are very kind and not cruel like people in the real world.

There is no pressure on me to try and understand why people act different in the countryside to those who live in big cities and have no time for others. This cottage represents peace and comfort for me in so many ways.

The skill of needlecraft brings many rewards for me and also gives pleasure to other people. The time taken to do it is lengthy but knowing that I am creating something worthwhile is enough for me.

**Julie Norman**

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### CUCKOO IN THE NEST

*A short story by Paul Kennedy, who has Asperger syndrome*

'We've found three more, Dr. Rowley!'

'What sort of condition are they in?'

'One looks to have been tampered with. It was decomposing; much of the liquid nitrogen used to preserve them seems to have escaped through a hole in the top of the casket, probably punctured by rocks. The body was minus a couple of fingers, probably cut off to get some rings to sell.'

'Animals!'

'And the other two?'

'One looks to have had his head smashed in with a hammer; no use to us, I'm afraid'

'Barbarians! And the third....?'

'Male. Obviously well preserved. Everything seems in working order.'

'Sounds just like what we are looking for. (Shouting) Take it back to the lab! I shall deal with it later; now round up a few volunteers for mopping up duty!'

'Yes, Dr. Rowley!' replied Rowley's assistant, like a raw army recruit, receiving her first orders to storm the nearest enemy fortress.

John Bunn was a baker, taken in his prime; or so it had been researched. In fact he had been ill with high blood pressure for quite a while; business had been slow and on hot days wasps caused him to destroy most of his livelihood, usually just after he had finished making it.

One very hot day, just before closing time, a gang came into Mr. Bunn's shop with the intention of robbing it. As he reached for the alarm, Mr. Bunn swallowed a wasp. Had the shock of the wasp stinging the roof of his mouth not killed him, the electrical discharge from the bug-killer he touched as he was writhing in pain would have. Bunn had been about to repair the bug-killer; it had been taken off the wall and was just about to be unplugged from the mains. On the day of his funeral, a note on the door of the baker's shop read, 'Sorry, Mr. Bunn the Baker is no longer at home!' Little did Mr. John Bunn know that he was to confront the legacy of Dr. Frankenstein head on.

Dr. Rowley and colleague looked at each other in amazement. 'What's it trying to say?' asked Rowley's colleague.

'Kangaroo!'

'I'm sorry!'

'Kangaroo! It's an old word meaning 'how should I know!' Apparently a certain explorer was so stupid, he asked the natives for the name of the animal. They replied 'Kangaroo!' i.e. 'How should I know!'

'Ooh, you have such a wealth of knowledge! I wish I had knowledge like yours!'

'Thank you, I know. I wonder if the subject is as primitive as that explorer. He looks like us, just different.'

'Know what you mean.'

At the party held for the people wishing to be frozen, there was not an air of fear of death so much as an air of expectation for the future. Many of the participants, through regression therapy, believed that they were in touch with their past lives. Mr. Bunn had met three former Queen Cleopatras, two Marie-Antoinettes and an Atilla the Hun. A physical reincarnation would, for them, be their greatest achievement in their dull existences according to Bunn. Many of those present believed that, in the future, technology would not only be able to revive them but they would once and for all defeat the aging process. Mr. Bunn's motives were clear; he wanted to bring the past to his descendants in a more tangible way than through books, particularly as he believed that the authorities tended to reinvent history to seek its own ends.

Sadly, however, Mr. Bunn found that he was unable to communicate with his 'descendants', despite the best efforts of Dr. Rowley and colleague, Mr. Bunn, the baker was in the same state as a newborn unable to speak, write or talk, his perception nothing more than abstract shapes.

Just then, there was a knock at the door.....

'Dr. Rowley, what prompted you to try to revive this person, something you know we hold as our greatest taboo, something that goes against everything we believe in?' asked the judge.

Rowley sneezed and sniffed twice.

'Dr. Rowley, I am waiting for an answer!'

Rowley coughed. There was a pause.

'Well?'

'For the advancement of our knowledge. For science,' sniffled Rowley. 'Yes, we have history books but they are tinged with opinion. I wanted to hear from the horse's mouth, so to speak, why all the men died out! Why do we have to lurk like Plato's....'

There was a blank look from the Judge as she looked through her spectacles at Rowley. The entire population of this world was female. Few needed to work out why all the men died.

"Plato..... he was an ancient philosopher. Plato's cavewomen."

Within three days, all present died of what was discovered from an ancient text to be "the cold".

The technicians who had frozen had assumed that as bugs cannot survive at -250°C, the temperature of liquid nitrogen used in the freezing process, it would not matter about sterilizing the outside of the canister containing the corpse. Because the area surrounding the canister was forbidden as there were dead humans there, this area was not purged when all illnesses were eradicated, ergo the bugs laid untouched. Since all illness was thought to have been eradicated, there was no need for treatment and there was no need for a resistance to disease. This was to prove very costly.

On the day of the hearing Mr. Bunn disappeared. His whereabouts are still unknown.

### ***Paul Kennedy***

*Asperger United would like to see more short stories being published so, readers, please start sending your work in*

*Editor*



## letters to the editor

### Why is the world not pragmatic like me!

I could not understand in my early years and in jobs why people talked about the weather and TV programmes and what they did last night. All that mattered to me, Lloyd, was doing the job only. Not talking about anything else.

I was very good in all my jobs but always got victimised with the rubbish jobs because I could not say 'no'. I also kept all my problems to myself which caused me a lot of stress. I'd come home very tired indeed and hungry because I only had half an hour for lunch, which I stuck to as I live by rules. The other staff would take longer than half an hour, which would annoy me very much.

All was explained to me this year when I was diagnosed with Asperger syndrome – aged 27.

What a relief to finally understand who I am.

**Lloyd**

### Prospective consultancy on Asperger syndrome

I am a young man who was diagnosed as having Asperger syndrome by Professor Digby Tantum of the University of Sheffield, in December 1996.

I have always found it a struggle to obtain information about Asperger syndrome and in particular information that would help me to cope with having Asperger syndrome.

Having Asperger syndrome I intend to run an Asperger consultancy where people with A/S and their families could obtain advice about A/S and advice on living with this condition. I would also arrange conferences for sufferers and professionals and write articles.

If you think this is a good idea then please write to *Asperger United* with your comments.

**Mark Bleasdale**

*Any comments sent in to AU will be passed on to Mark*

*Editor*

### Dear Asperger United

I was wondering how other people on the autistic spectrum cope with noise. I am very sensitive to noise and modern life is so noisy.

I find the noise of traffic, fireworks, loud music, shopping tills, mobiles and walkmans very distressing.

I moved my bed into my living room because my next door neighbour's TV could be heard in my bedroom and I like to go to bed at 10pm, as I get tired easily. And I have just got my downstairs neighbour to keep his noise down too. I can't tolerate earplugs so it's really hard to deal with.

I wonder how other people cope with oversensitivities and overstimulation. Even bus rides and supermarkets 'overstim' my head and make me anxious and agitated.

**Yours Ali**

### Dear AU

My local Asperger syndrome social group are a collection of individuals of all ages, sizes and abilities and generally we get along well.

We recently spent a night together in a youth hostel. It went well but later on in the evening a few of the members became irritable with each other and we all felt quite dislocated from our normal routines.

The second day was a beautiful crisp autumn day and we decided to go for a walk. This went well but we have a great range of abilities and whilst some of us are very ardent walkers others are quite unused to physical activity. Whilst we were debating the length of the walk one member made a very personal comment to another about their level of stamina and weight – with the usual level of Asperger sense of diplomacy.

However, we eventually got going and were able to converse well together. Later we had a meal and by that time tempers were becoming strained within the group. People with Asperger syndrome often struggle to comprehend and respond to humour.

We hope other AS groups in the country, such as the one in Leicester, manage to get away together. If so, why not share your experiences with us?

**Anon, Nottingham**



## How to reply to **Pen Pals**

- Please remember to let us know the full name (including surname) of the person who your letter is for.

- 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 penpal letters sent via *Asperger United* are opened before being passed on

- Young people under the age of sixteen must have parental permission before placing a pen pal advertisement in *Asperger United*.

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My name is William. I am 37 and have Asperger syndrome/autistic tendencies. I am looking for female companionship in the Portsmouth/Hampshire area.

My hobbies are drama, reading and going to the cinema.

Thank you.

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My name is Lloyd. I'm 27 years old and have Asperger syndrome. My hobbies include reading, computers, internet and sci-fi films. I'm also very interested in flags and politics. My favorite music is 80's music.

I am looking for pen-pals who have Asperger syndrome and live in the Croydon area.

Thank you

Lloyd

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## The Autumnist

Its colours are dazzling me  
Its smells are fizzling me  
Its cool moistness is sizzling me  
Its mellowness is nuzzling me  
Its shortness is puzzling me.  
I think I'm on the autumnism spectrum, somewhere.

## Michael Mitchell

*Thank you Michael*  
*John Joyce*  
*Editor*

## The Missing Heart

Where are you?  
I know your location  
I feel your beat  
And you must be pumping my blood around  
But that's just the mechanics  
A machine could do the same job  
  
When I ask where you are  
I mean the heart I've read about in romance novels  
The one which inspires songs  
The heart people claim to lose or break  
The one people rule with and wear on their sleeve  
Where is the heart that aches  
The one that loves completely?  
I wish someone would tell me

## Anon

*Thank you Anon*  
*Where have you gone*  
*A fine sonnet*  
*No name upon it!*

*John*  
*Editor*

## I Know

I know people are not what they seem  
They say one thing and do another  
They smile to your face  
Then moan behind your back  
Their body language tells one story  
While their lips tell another  
And their eyes just add to the confusion  
Wouldn't life be much easier  
If people simply told the truth?

I know what good manners are  
But don't see the point of etiquette  
I know I have to say no  
Even if I want that last piece of cake  
I know I have to lie when my partner asks  
'Does my bum look big in this dress?'  
What's the point of people asking  
If they don't want to hear the truth?

I know there are a lot of hypocrites  
Where's the sense in etiquette  
When we are destroying our planet?  
How can a nuclear scientist  
Be too afraid to break social norms  
Then happily go to work  
To create weapons of mass destruction

I know one thing for certain  
Mother Earth won't tolerate our bad manners  
For much longer  
So, yes, thanks,  
I think I will have that last piece of cake

## Anon

*Another good poem*

*John Joyce*  
*Editor*

## Excitement

A coming alive of the human spirit  
An awakening of Happiness.

Kerr

**Dear John**

Thanks for the *Asperger United* Anthology. There were some very good poems and stories in it.

It would appear that many people with Asperger syndrome like to write poetry and, though I am not good with words, I sometimes have a go myself. So I'm enclosing my latest effort. Sorry it's so negative, but that's just me I suppose...

Perhaps I can use your letters page to say a big 'Thank you' to Asperger Norfolk and all those involved for showing me friendship and giving support.

Regards

**Tom**

**What must it be like?**

What must it be like to help other people  
To be wanted and needed, to be really useful  
What must it be like to wake up each day  
With a purpose and belief you'll succeed come what may  
What must it be like to have family and friends  
Who care that you're here, and stand by you to the end  
What must it be like to have someones respect  
To make your mark in the world, to have an effect  
What must it be like to live without fear  
To meet life head on with an aim true and clear  
What must it be like to fulfil your ambitions  
To have all of your dreams come to fruition  
What must it be like to have help from above  
To feel that you're special, to have someone's love ...

**Tom**

*Another poet who does not know it - good show Tom.  
Not good with words!!  
Whatever do you mean? - John Joyce*



**Autumn**

**Tim Loder**

Autumn, Autumn,  
It is Autumn  
The leaves are-a-turning  
The squirrel is-a-scurrying (for nuts)  
His tail is-a-flurrying

Brisk is the wind,  
Through leaves-a-whispering  
And then the blast,  
The leaves fall a-fast,  
Indian Summer's now-a-past

Autumn, Autumn,  
It is Autumn  
The Swallows-a-part,  
Are-a-departing

**Tim Loder**

*Thanks Tim - another poem of class  
John Joyce - Editor*

## Coping with Obsessions and Routines

My name is Michael. I am 27 years old and was diagnosed with Aspergers syndrome several years ago.

Ever since I was young I have had many obsessions and routines which used to rule my life. I was continually asking Dad to draw snowmen, which he did, according to specific instructions and I would arrange them in a specific order.

Unfortunately my little brother often disturbed the order and tore the snowmen into pieces and I would get terribly upset whenever this happened. As well as this, I enjoyed lining up my soft toys before going to bed.

I was also fascinated by the sound of doorbells and constantly rang them every time I passed a house with one to see what it sounded like. Mum told me not to do this and when I did, she would apologise to the owners. I couldn't understand this but now I can.

As well as these obsessions, I also had fixed times for everything: meal times and bed times were fixed, as well as other things.

As I matured, the snowmen and doorbells gradually subsided (thank goodness!) and I started to play and listen to Christmas carols. This was the obsession that really took over my life as I enjoyed the music so much that I could not have any time without them.

At this time, in around the year 1999 I met my psychologist, Alicia, who diagnosed me with Asperger syndrome and helped me learn how to relate to other people and get my obsessions under control.

She did this by suggesting that I should only spend up to one hour a day on obsessions. She then provided me with some techniques to help me relax so that I did not depend upon my obsessions to do this.

I found this hard to understand, so I ignored nearly all she said and constantly passed the one hour limit and mum and I kept arguing about how much time I had.

Now I am gradually becoming aware of how others feel and I am starting to control my obsession time by myself.

As the years go by, I have tried to reduce my obsession

time by one hour per week, so now I only do five hours a week, although I still talk about it and occasionally think about it outside my time.

I am now having one week a month with a further hour less obsession time in order to cope with exceptionally busy weeks and to reduce my obsession time even further.

I don't have fixed meal times and bed times any more, but there are some routines like folding up towels which I still do.

I never understand why others found my obsessions boring. They are like schoolwork to me, but more enjoyable. Unfortunately, people don't seem to think in the same way that I do. People just find my obsessions boring, irritating and embarrassing. People fail to realise any uses for my obsessions.

I have recently been obsessed in writing a 50-page document on social skills, which will help me in later life.

I am now in the sixth form at school, and everything is different. I am gradually coping with the new routine, particularly having more free time and independent study time. At first I got bored during the free time but soon found things to do and I am also getting used to lessons being cancelled on the spur of the moment.

I would be very interested in hearing from anyone of similar age with similar difficulties, particularly in the Buckinghamshire area.

### Michael West

*Michael, this is a really interesting article - thank you for sending it in.*

*Readers, if you have similar problems with obsessions and routines and have found strategies for keeping them under control - please write in and let us know.*

*John Joyce  
Editor*



*'Country Scene' by Julie Norman*

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## My story - by Stephen

Hello, my name is Stephen. I was diagnosed with Asperger syndrome about five years ago, when I was 32. I get full benefits, have my own flat, and am loud and proud.

When I was a child I used to play up a lot and display odd behaviour. Due to this I was sent to a school in Oxford for children with behavioural problems. When I left I went to a school in East London. I continued to play up, e.g. by dressing up as a woman – simply as a dare - and doing a 'mooney' at the headmaster. I was excluded for this, which didn't bother me as I used to bunk off most of the time anyway.

I got involved in music and claimed social security. I met lots of famous people and nearly made it as a rock star. I could have been really big, as I was good looking and, more importantly, a gifted musician. Things though didn't work out for other reasons.

I messed around and got into a lot of trouble and drank too much. I got in trouble with the police and was linked to various incidents, none of which had anything to do

with me. Simply wrong place, wrong time as Aspergers often are.

I've been arrested and sectioned many times. I was wrongly diagnosed and given unsuitable medication. I once escaped from a hospital through a window and am currently fighting them for compensation.

I'm currently in prison – I was drunk one night and someone accused me of something. Basically I was 'stitched up' and am currently appealing.

When I get out I want to settle down a bit. I'm going to try and get back into music and make a success.

When I look back on my life I think 'Jesus, I certainly left my mark'

To all you fellow Aspergers – be proud, we are really special, unique people. Like me, fight back and don't let them push you around.

**Stephen**

## New book news

### *Freaks, geeks and Asperger syndrome* By Luke Jackson

Luke Jackson is a most unusual person: not just because he has Asperger syndrome but also because at the tender age of 13 has already published two books.

His latest book is *Freaks, geeks and Asperger Syndrome*. This is an honest and witty guide to the hazards and pitfalls of being a teenager with Asperger syndrome. It covers everything a teenager should know about growing up, including difficult topics such as bullying and dating.

There is very little other information available for teenagers with Asperger syndrome so this book fills a very important gap. It is full of down-to-earth and sensible advice and information. It is sensible but never preachy.

Luke has also made use of the advice of his teenage brothers and sisters to make this book really accessible and useful to all teenagers with Asperger syndrome.

Like all the best books on autism and Asperger syndrome, *Freaks, geeks and Asperger Syndrome* is available from NAS Publications and is published by Jessica Kingsley Publishers. It costs £12.95, plus postage

and packing.

Luke's first book, *A user guide to the GF/CF diet for autism, Asperger syndrome and ADHD*, was published last year when he was just 12. It also costs £12.95 and is available from NAS Publications.

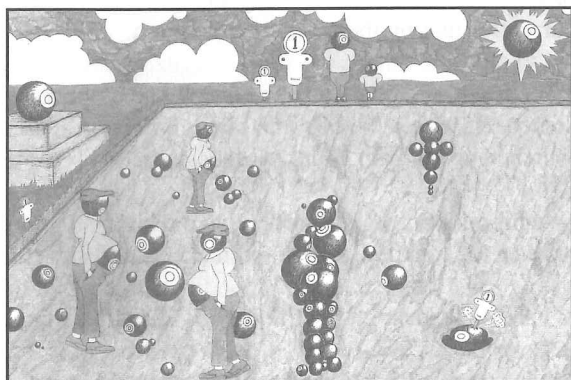
### **Special offer to readers of *Asperger United*!**

Normally we charge an additional £3 for postage and packing on all book orders but readers of *Asperger United* can get their copies without this additional charge until 28th February 2003.

Just send your order, together with cheque or postal order made payable to the NAS or your credit card details, to *Asperger United* – see page 2 for full contact details.

Please also send us news about any other books that you think readers of *Asperger United* should know about.

## Last chance to buy Peter Myer's postcards



We still have a few packs left of Peter Myers beautiful postcards.

These original and colourful cards are available from the NAS at a special price of £2 per pack of ten postcards, including postage and packing

Please send a cheque or postal order, made payable to the National Autistic Society, to *Asperger United* (address on page 2) stating how many packs you would like.



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