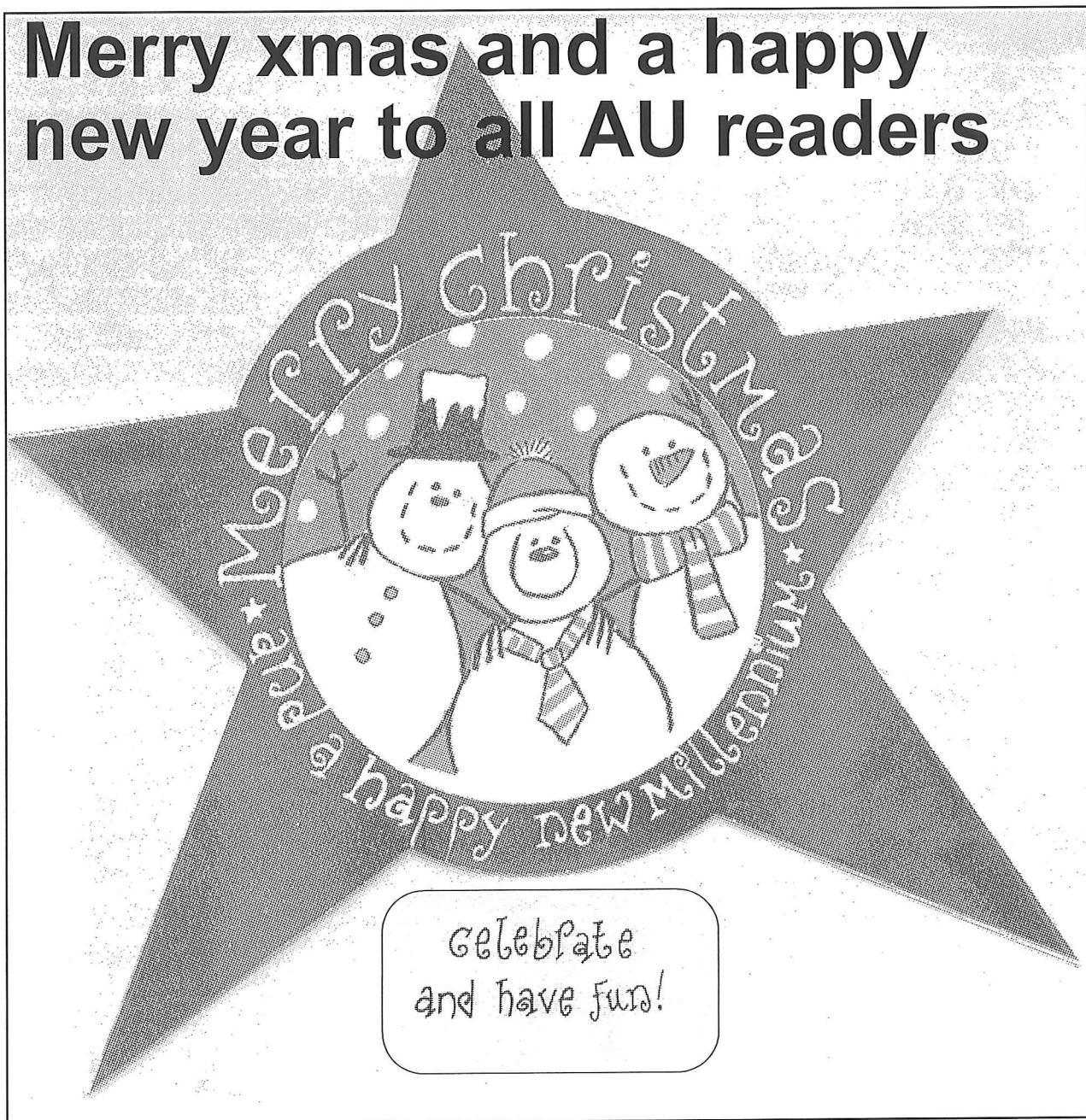


Produced by and for people with Asperger syndrome

united Asperger

Edition 22 Winter 1999

**Merry xmas and a happy
new year to all AU readers**





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 produced by an editorial group consisting of:

Editor John Joyce

Sub-Editor Martin Coppola

Assisted by Pam Yates, The Maudsley Hospital's Home Based Team for Autistic Individuals

Additional support from The National Autistic Society

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Please send all correspondence to

Asperger United, c/o The National Autistic Society,
393 City Road, London EC1V 1NG.
Fax: 0171 903 3767. Email: asp.utd@nas.org.uk

For enquiries about *Asperger United*

Tel: 0171 903 3540. Email: asp.utd@nas.org.uk

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 Editors, The National Autistic Society or those involved the publication of the newsletter.

Dear Readers,

Welcome to the latest edition of your magazine which will hopefully reach you all before the festivities of Christmas and New Year.

I must first congratulate those of you who described your feelings about your situation in the programme *Up Close and Personal* on Sunday 14th November on ITV. You were all very articulate, showing our common communication difficulties are being overcome. See also 'Well done all' on page 4 where we congratulate all, but also Robin Oliver who has not only appeared in *Up Close and Personal* but also appears in a new video entitled *The ages of autism*, where he talks about having Asperger syndrome.

In my own case I have perhaps witnessed the other side of communication problems. My recent Open University exams required me to listen to recorded tapes (in French) and then comment in the same language on what I had heard and also on two texts I had read. My listening equipment failed and I was not able to properly listen to the tapes. I fear I may have failed

the exam, maybe this time not allowing me a re-take.

Enough about me, I hope all of you are getting on well. Those of you who have jobs will hope to be keeping them and a few more of you will hope to be getting them. Perhaps after the programme, 'Up Close and Personal', one of our interviewees could see him/herself as a TV presenter!

Any of you who have interesting stories about holidays, interests and jobs, or have some poetry, perhaps a short story or any other literary gems should not be afraid to send these in to *Asperger United*. We are always looking for new stories to fill the pages this newsletter. So, do send them in!

As this is the last edition of the year/century/millennium, may I wish you all the blessings and happiness of Christmas and a happy and fulfilling new century year.

Your friend and editor,

John Joyce

Contributions needed for the next edition of Asperger United

Asperger United will be published during March, June, September and December 2000. Please do send in any stories, articles, poems, pen pal requests and letters.

The new millennium – your thoughts and hopes

If any readers would like to write about their thoughts on, and hopes for, the new millennium we would like to publish such articles in the next edition, out in March 2000.

Contribute to your newsletter

We are always looking for new ideas and stories to fill the pages of the newsletter. We would like to hear any news, receive articles about yourselves, see your artwork and read your poems and short stories. So, do send them in!

Send all contributions to:

Asperger United
c/o Publications Department
The National Autistic Society
393 City Road
London EC1V 1NG.
Fax: 0171 903 3767. Email: asp.utd@nas.org.uk

in this edition

| | |
|--|----|
| editorial | 3 |
| news | 4 |
| feature: My life, a bestseller! by Philip Snell | 5 |
| letters to the editor | 6 |
| pen pal network | 7 |
| feature: My alternative perspective by Ross Gordon | 8 |
| feature: Learning to drive by Samuel Holmes | 10 |
| talent scout: artwork of '99 | 11 |



Want to know more about the artist?

Peter Myers has kindly been producing artwork for inclusion in *Asperger United* for many months now. We hope to be able to continue printing his artwork. In the next edition we also hope to be able to tell you a little bit more about Peter and how he got involved in art.

If there are any other budding artists who would like to see their artwork printed in *Asperger United* then please do send in your art.

Lifeline

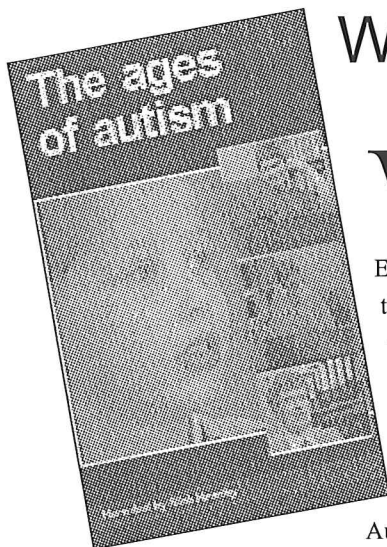
Many people with Asperger syndrome rely on the internet and e-mail for communicating. My telephone bill has come recently, and because it was well over the odds, I had to be disconnected as a result.

I have really enjoyed using e-mail, and have made a friend in doing so, something that would have taken a lot of courage to do face to face. It would break my heart if I lost him, because it feels like he's the only friend I've got.

That's why I'd like the government to introduce a special freephone internet number, so that people with disabilities (and Asperger syndrome) can use the internet and e-mail without worrying about paying a massive telephone bill.

Please write to your MP's, because this is my one and only lifeline. After the recent debate in the Lords about the curbing of Disability Benefits, people with disabilities need to communicate more than able-bodied people.

George Handley



Well done all

We were all impressed with – and would like to congratulate – those people who took part in the programme *Up Close and Personal*.

Everyone who took part in the programme was able to talk about having Asperger syndrome in a very clear and way.

Further congratulations must also go to Robin Oliver (who has contributed articles to *Asperger United*) for his appearance in *The ages of autism*, a new video (produced by Mark It Television with The National Autistic Society) looking at autistic spectrum disorders

and how the condition affects people of differing ages and abilities.

In the video, Robin talks about his experience of having Asperger syndrome and how a supported employment services has helped him at work. We done Robin. You are every bit the TV and video star!

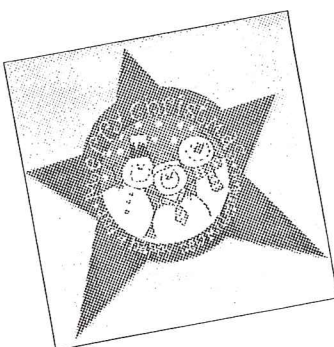
Write away!

If any readers would like to write about their personal experiences of having autism or Asperger syndrome then we would like to hear from you. *Asperger United* is always keen to receive articles and stories about *you* – the readers.

The National Autistic Society (who publish *Asperger United*) would also like to publish some of your personal experiences on it's website. If you would like to write an article or story for use on the NAS website then do send them in to: The National Autistic Society, 393 City Road, London EC1V 1NG. No article or story will be used without your consent.

and finally...

All at *Asperger United* would like to wish our readers a very Merry Christmas and Happy New Millennium year. We would also like to thank you all for continuing to make AU a great success. We hope you will continue to send in your contributions and make 2000 another great year for the newsletter.



My life, a bestseller!

I have often thought if I were to write my life story it would be a 'best-seller', but have never got round to doing anything about it. Your magazine, however, has prompted me to put pen to paper. So here goes!

I am 42, single, and live alone in Norwich. I was only diagnosed with Asperger syndrome approximately 12 months ago, which came as quite a revelation, as I had never previously heard of the condition. My brother, who is 34, and single, also has Asperger syndrome, and he too, was only recently diagnosed. I suspect the condition in my family may be hereditary, as my late father, although possibly not actually having the condition, certainly showed my symptoms.

I grew up in Birkenhead, and as a child was bullied remorselessly at school. The children used to make my life an absolute misery, to such an extent that I eventually left school prematurely, and finished my education with a home tutor. I did not take any qualifications and indeed, I began what I now call a 'downward spiral'. I spent a large number of years in and out of mental hospitals, and was practically used as a human guinea pig judging by the amount of medication I was subjected to.

My family moved to Wrexham, in 1971 due to my father's job, and in 1981 I decided to leave home, and start life on my own in Chester.

I have never worked, and indeed, to this day suffer from a giant inferiority complex, which is a great hardship. I do not mix well and have very few friends, indeed, all my life I have been lonely.

In 1985 my father died, and I became increasingly drawn towards the Church. I am now very religious by my own definition, and find it a great help, I am C of E

and a high-Anglican.

In 1993 I lost my mother, and I now have virtually no contact with my few remaining relatives. My brother and I are best if few are at 'an arms length'.

In 1998, I took a bold step, and decided to start a new life for myself in Norwich. I have recently found myself a very nice flat, and I am now applying to join var-

“ I have often thought if I were to write my life story it would be a ‘best seller’, but have never got round to doing anything about it. Your magazine, however, has prompted me to put pen to paper. ”

ious local groups and societies to try and meet people. As I said earlier, it's extremely difficult for me in social situations, as it always has been, and I often become very frustrated.

On occasions, that frustration has turned to anger, and aggression, and indeed, I have unfortunately fallen foul of the law on a couple of occasions.

People, at large, are unfortunately very ignorant of Asperger syndrome, and so find it difficult to comprehend why I behave as I do, especially at nearly 43 years of age! Consequently I find I tend to get little if any sympathy when things go wrong, due to ignorance.

Within the last 12 months or so, I have also come to the conclusion that I am gay, which only seems to make matters worse.

I find the frustration so much more difficult, and the opportunity of meeting people is a problem which seems insurmountable.

I feel there must be other gay people out there with Asperger syndrome – but at present I feel in a minority of one! I often feel that it's like having two crosses to bear!

My interests are very much in the cultural field, I love historic buildings, architecture, churches, stately homes. Railways and the theatre. I have lost count of the number of stately homes and churches I have visited and I possess a large collection of guide books to all those I have been to. I have also a huge collection of videos, mainly of railways, which I watch, when I am at home. I spend most of my time out all day, and enjoy visiting all the many churches, which Norwich is justly famous for.

I do not cook much for myself, as by my own admission I am a lazy cook. Someone once said "Philly, is a good tin-opener!" I use a microwave, but mostly prefer to eat out, as I am glad of the company.

I enjoy walking, and so quite a lot. I have only today walked along a footpath which had recently opened near me, which used to be a railway line. I found this very interesting and enjoyable.

I think perhaps I have told you enough for now, as I really could write a book. I hope you will excuse my frankness, as I have tried to be as open and truthful as possible.

I am also connected with Asperger Norfolk. If you are interested they are based at Old Lion Cottage, Thurne, Great Yarmouth, NR29 3AP. Tel: 01692 670864.

Philip Snell



“ I wonder if anyone with Asperger syndrome has considered Open Learning and Open University courses instead of the mainstream courses? ”

Dear *Asperger United*,

I feel privileged to be able to subscribe to *Asperger United*, as I haven't been diagnosed with Asperger.

I have 'Kline Felter's Syndrome' – a sex chromosome abnormality/ sex hormone deficiency, genetic disorder. Kline Felter's is very much like Asperger syndrome and I contacted Dr Simon Baron-Cohen, (over a year ago) to see if he was interested in the links between Kline Felter's and autism/ Asperger syndrome.

He was, and has been researching it since then. I recently saw an article from a conference in the USA about Kline Felters, that mentioned, 'sensory Overload'.

I don't know how this could affect us with Kline Felters, but wonder if it could cause headaches, severe anxiety and concentration problems. Do these effects occur in Asperger folk with sensory overload?

Reading through copies of *Asperger United*. I was struck by how many Asperger folk have failed to finish exams at University and College due to their personal problems and breakdowns. I wonder if anyone with Asperger syndrome has considered Open Learning and Open University courses instead of the mainstream courses? I thought working at home would be less stressful and you could pace yourself to your own rhythm to which you want to work.

If anyone would like to write to me, please do. I can relate to folk who self injure, as I have done since I was a teenager and still do at 38-years-old.

I have also had a lot of success with FLUANXOL, a drug to prevent severe anxiety/depression and paranoia.

Tom Lee

Reply from the editor

Tom, I am currently on an Open University course. In the next edition of *Asperger United* I will write about my being on the OU course. Sorry I can not answer your question now.

Your editor, John Joyce

Disappointed by conference

Dear *Asperger United*,

I am writing about the Asperger Conference held in October, which I attended, I would like to offer the following observation which I also made to the organisers on the conference evaluation form:

Venue

I considered this to be unsuitable, as it was very noisy at break times, coupled with the appalling PA system, I found it extremely and stressful to try and hear what was being said.

Lunch

Considering the high cost of the conference the lunch was just adequate, however what was most upsetting was the fact that there was very few places to sit and eat, I personally was moved twice by college security staff, and had to eat my lunch standing up in a very crowded hallway.

Speakers

I considered the balance of subject matter offered by speakers to be well balanced, however I felt extremely sorry for them as they struggled to make themselves heard. I was particularly embarrassed by the Chairperson's treatment of Dr Amita Shah, and the other lady Doctor, I felt it was disrespectful to them.

The speakers I found most interesting were Dr Paul Gringrass, and Dr Sidney Chui, as I felt that their lecture contained information that I personally had been aware of for sometime, it was so exciting to hear it. I am so glad that I managed to get them down despite my difficulties hearing and concentrating.

Katie Fisher, Croydon Asperger Syndrome Support Group

Reply from the editor

Sorry to hear that you were disappointed by the conference. I am glad to hear you let the organisers know by filling in the evaluation form. Do any other readers have any views on the conference?



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.
- ❑ If you would like to write to 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 onto the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.

David Hodder, Camberley, Surrey

Hi, I'm David, 38, I've had Aspergers all my life. I would like a kind, caring, understanding girlfriend to be happy with, though I will never be able to marry or have kids. So, if you're female, and like to have fun, please write, look forward to hearing from you.

Philip Snell, Norwich

My name is Philip. I am single, 43 and live in Norwich. I am not working at present, although I am involved in some voluntary work and I belong to a number of local clubs and societies.

My interests include theatre, architecture, walking, and antiques. I am also a practising Christian. I would like to hear from anyone in any area who might like to be a pen friend.

Richard Richardson, London

I am interested in riding my bike, playing my Playstation computer, which I like. I would like to meet and/or write to someone with the same interests as me. I don't mind if it is male or female. I would like a pen pal between the ages of 20-23

years who lives in the London area and who is into the latest pop music.

Anthony Cresswell, Nottingham

My name is Anthony, I am 27 years of age and I live in Nottingham. I am interested in religion and spiritual growth. My hobbies include endurance exercise with weights and country walks. I like New Age music, stone circles, woodland, autumn colours, rain and thunder, stones and gems, the night sky, incense, aromatherapy oils, and massage, wine and organic ales.

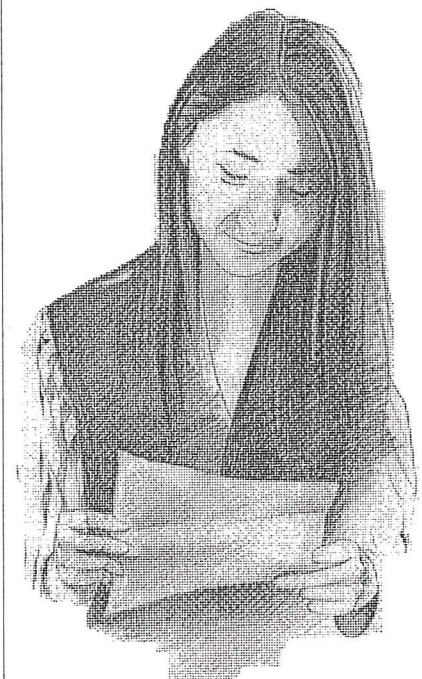
Sandra Jackson, Ilfracombe, North Devon

My name is Sandra, I am 33 years old, live in the North Devon area and was diagnosed as Asperger the latter part of last year.

For the last year I have been living independently and cope reasonably well. However, since I have problems forming relationships, because of my fear of communicating verbally, I find myself feeling increasingly isolated.

My immediate area has no facilities and little support for people like myself to network with others. This of course makes my situation worse.

I love writing and I would love to hear from others who suffer from the same day to day frustrations, to share ideas, information and friendship.



Ross Gordon writes about where he feels he relates to the chapter about Temple Grandin and Asperger syndrome (in Oliver Sacks' book *An Anthropologist on Mars*)

My alternative perspective

When I was young I was always in trouble for what was interpreted as disruptive and antisocial behaviour. I have always been seen as stubborn, tenacious, single minded and brave (stupid?) for the way I stand up to authority. Child psychologists and teachers blame my mother who showed no love whilst prison staff blamed me and punished me by isolating me in the block, which I loved. At the age of 36 I was put on drugs for schizophrenia due mainly to my anti-authoritarian behaviour not matching my academic achievements. Eighteen months later another doctor decided that I was not a schizophrenic and my medication stopped. I have been called an attention seeker, obsessive, compulsive, unemotional etc.

I could not speak properly and my elder sister was the only one who could interpret what I was saying. I was sent to a speech therapist and taught how to make recognisable sounds. I practised and memorised lip patterns, mouth movements and tongue positions until speech became second nature.

I had peculiar and intense preoccupations and fixations. I was always socially withdrawn and remote. I could spend hours in my own company concentrating on whatever I was interested in at the time. I could concentrate so intensely that I did not feel pain to the same extent as my brothers and sisters. I still prefer to lock myself away and get on with puzzles or problem solving or studying. I found I was good at maths and I could get lost in its safe world. Hours would pass as if

they were minutes. I have total concentration in this and other fields and nothing can disturb me when I am in this mode. People find it difficult to understand how I can spend so long studying without a rest and they say I must learn to relax. It is hard for me to explain that when I study I feel relaxed but when I am doing activities which they feel are relaxing I am in fact under pressure, because I am having to constantly assess situations to try and behave appropriately. I was also very selective with my attention and could quite easily blank out the rest of the world as if it did not exist. It was much easier to be in this world with my imaginary friends and be myself rather than trying to live in the real world with the effort of selecting appropriate behaviour.

I have trouble socially with verbal and non-verbal communication unless I have encountered the situation before and have a programmed response ready to reproduce. This is almost second nature now

I have trouble socially with verbal and non-verbal communication unless I have encountered the situation before and have a programmed response ready to reproduce.

with familiar situations but not with new situations. In such situations people think I am very quiet and shy when really I am watching and recording as much as I can so I will be better next time. I taught myself to get by in a lot of social situations but my attempts at emotional responses come out as stilted. I find it difficult to be spontaneous because my mind is analysing a range of pre-programmed responses before choosing what I consider to be the most appropriate. Sometimes I get it wrong and people give me strange looks so I double check my intended response which further slows down my attempt at spontaneity. When I respond spontaneously I always get it wrong. For instance, when I told a work colleague some good news, she reacted with joy and threw her arms around me to give me a hug. My immediate response was to step back in horror which upset her. She took it personally and kept saying "You don't need to explain" as I attempted to let her know that I have a dislike of physical contact. The truth is I hate physical contact, but have now learned to put up with it if it is expected or anticipated but not if I am taken by surprise.

People tend not to understand my way of thinking which offered what was to me an alternative perspective. I just felt that their narrow ways of thinking meant they missed out on so much. Peers often said I was incredibly stupid for an academic and could not understand how I could possibly have achieved what I have. Most want me in their quiz team

“ People tend not to understand my way of thinking which offered what was to me an alternative perspective. ”

and are disappointed that I know very little outside my own field.

I have set routines. For example, I respond to my letters on the last Tuesday of each month. If I do not catch up with them all then the rest wait until the following month. I only really write to friends out of a sense of duty and feel I have much better things to do. Also, I can understand why people like to use the phones, but this is only on an intellectual level. Emotionally, I cannot empathise and see the phones as a waste of time and money in the prison setting. However, I do use the phone once a week because my friend sends me money for phone cards. I spend it on phonecards which I only use on him but I find it difficult to communicate. When I have used the last card I tell him I won't be phoning again as the cards are now used but he sends some more money and the process is repeated. I never use all my visiting orders as it is an effort to concentrate on appropriate social behaviour on a one-to-one for two hours. I would much prefer to have no visits at all but understand that some people want to see me so I make the effort.

I lack self-consciousness in a lot of situations and people ask “aren't you embarrassed?” to which I reply “Why should I be?” I enjoy being childish and playing practical jokes. I am very loyal to my friends to the point of self-sacrifice.

Like Temple I seem to have a natural empathy with animals and relate to them much better than I do with humans. The animals seem to understand this and I seem to be able to gain their trust and

train them very quickly. I also seem to get on better with people with disabilities than most other people.

I am over-sensitive and under-sensitive in many situations and have periods of backsliding and regression. I also have periods where I make tremendous strides forward and nothing seems to go wrong. I have trouble understanding others' pleasure or sadness. For example, recently there has been a fuss about the eclipse, but to me it was not worth disturbing my work to watch. I just couldn't see the point. Similarly, when Princess Diana died I could not understand all the fuss and I was doubly confused to learn how little fuss there was at Mother Teresa's death a few days later. She had done so much more good than Diana and yet there was not half as much fuss.

I have had sexual relationships, though I have done so out of a sense of duty. It is the appropriate thing to do to be 'normal'. I find it much easier in platonic relationships but the fact that when I speak to girls I am not just trying to get them into bed seems to make me more attractive to females. I am often told how nice I am as a person but often there comes a point where sex is expected as a natural progression. I do not really know what it is like to feel passion for someone, but I have learned to behave as if I am in love.

Ross Gordon

Would you like to write an article for AU?

If you would like to write and send in an article for publication in *Asperger United* please feel free to do so.

When writing an article please try to type it up and then send in a printed version or write the article in clear handwriting.

Send you articles to:

Asperger United, c/o Publications Department, The National Autistic Society, 393 City Road, London EC1V 1NG.

Here Samuel Holmes writes about his experience of learning to drive in his thirties – after being diagnosed with Asperger syndrome

Learning to drive

I don't think I will ever forget the day my mum told me about my Asperger syndrome. I had just had an argument with one of my sisters and I asked my mum why I was like this, always getting cross, taking things too seriously. When she told me about my condition, I wasn't really very surprised, since I had always wondered if I had some disorder which was responsible for many of my characteristics. My mum was worried that knowing about my condition might upset me, but I took it very well. I actually felt I was special, I had something my classmates didn't, that couldn't be taken away.

Once I knew about the condition, I thought about it quite a bit. I read Tony Attwood's book *Asperger syndrome – a guide for parents and professionals* and began to learn about the condition. I could see things in the book which described me, although I had never really had Asperger syndrome very badly. Then, one day I just stopped thinking about my disorder. It wasn't that I didn't care, I just became occupied with other things.

It wasn't until I started to learn to drive a car that I began to wonder about my Asperger syndrome. I began to wonder how it would affect my driving. Would I be able to cope with the ever changing traffic situations? Would I remember how to do things I had been taught in the previous lesson? Would I quickly master the skills, or would I still be struggling along trying to learn to drive when I was in my late 30's?

Fortunately, things weren't as bad as I had expected. I managed quite well, and

was able to master new skills with practice. There were just a few problems: Any time my parents corrected my mistakes, I took it really personally, and got cross, accusing them of "Getting at me". I also tended to lapse concentration, and when driving this is dangerous, and I had to work really hard to keep concentrating.

Another problem, I found, occurred only when driving at night. I seemed fascinated by the light from the head lamps of oncoming cars, and would move out towards the centre of the road, as if drawn towards them. I had to practice hard to correct this. But things didn't stop there. If I had had a bad driving lesson, instead of saying "Ah well, I'll try again tomorrow" and going on with it, I got really angry and upset and started talking about giving up driving. The only reason I didn't give up was because I had always given things up. I was fed up with quitting when things went wrong. I also wanted to be independent of my parents, not that there is anything wrong with their driving, but there would be times when I wanted to go somewhere and couldn't because my parents were busy working, or away, and unable to drive me there.

My lack of patience also played a part. I would get impatient with my parents, I would get impatient with driving. I wanted results immediately. I knew that driving took practice, but I just couldn't grasp the logic that someone who has been driving for only a few weeks (me) won't be as good as a person who has been driving for 31+ years (my dad). Once I settled down and concentrated, I was OK.

“ It wasn't until I started to learn to drive a car that I began to wonder about my Asperger syndrome. I began to wonder how it would affect my driving. ”

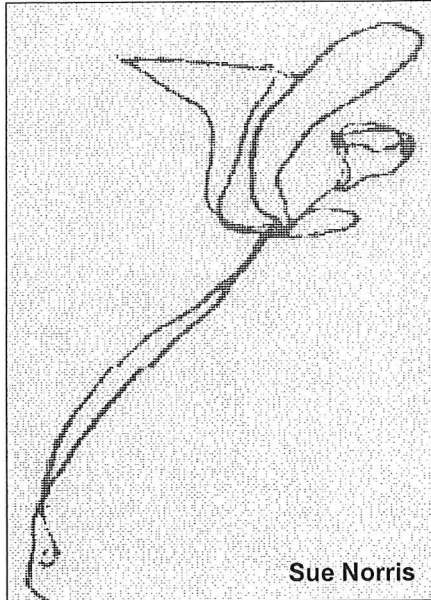
Another problem which certainly didn't help was the fact that I let things get to me. If I am upset, or was cross, or annoyed with someone, I let it build up inside me instead of letting it go. As a result, my driving often suffered while I was learning.

My driving has really come on now, and I do make the occasional mistake, but that is perfectly normal for a beginner driver. And I'm much more understanding with my parents. When they correct a mistake, I apologise politely, and remember not to make the same mistake the next time. I took my test on 12th October 1999, and I passed first time, much to my surprise!

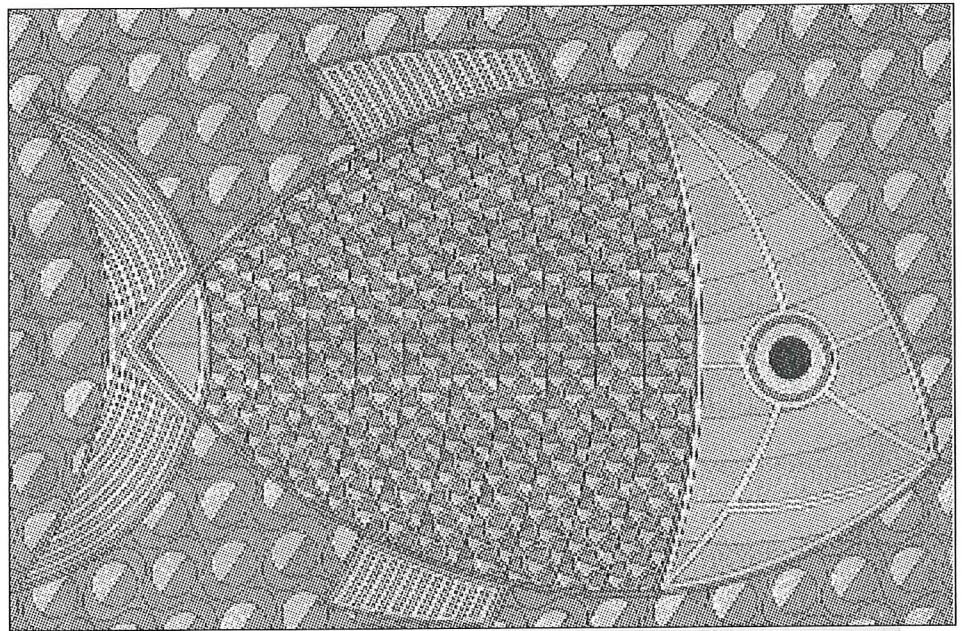
Learning to drive has been an interesting experience, both for me, and for my parents. It has also been a learning experience. It has taught me that sometimes it is better to slow down, and think before acting. It has taught me to be more mature, to put childhood behind me. And, to a certain extent it has also taught me that just because a person has Asperger syndrome, doesn't mean that they can't do things that other people in their age group can. It may take a little longer, it may be very much harder, but if they soldier on, they can achieve almost anything!

Samuel Holmes

Artwork of '99

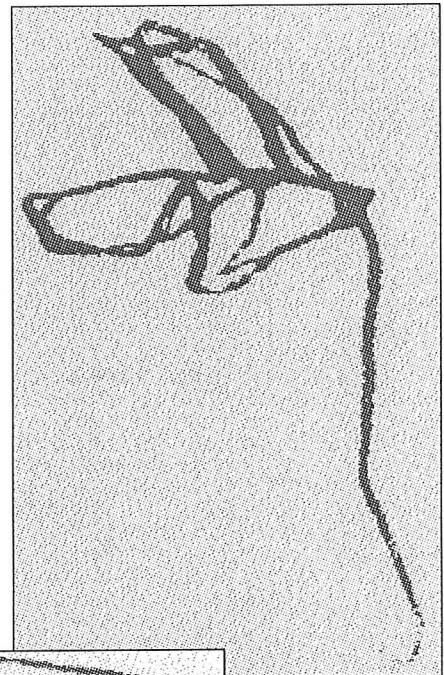


Sue Norris

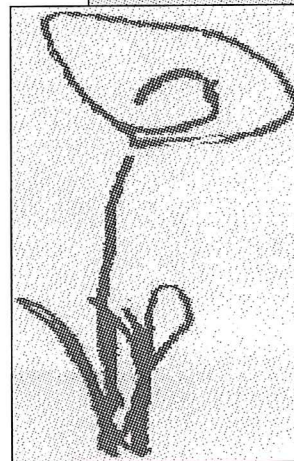


Fish by Peter Myers

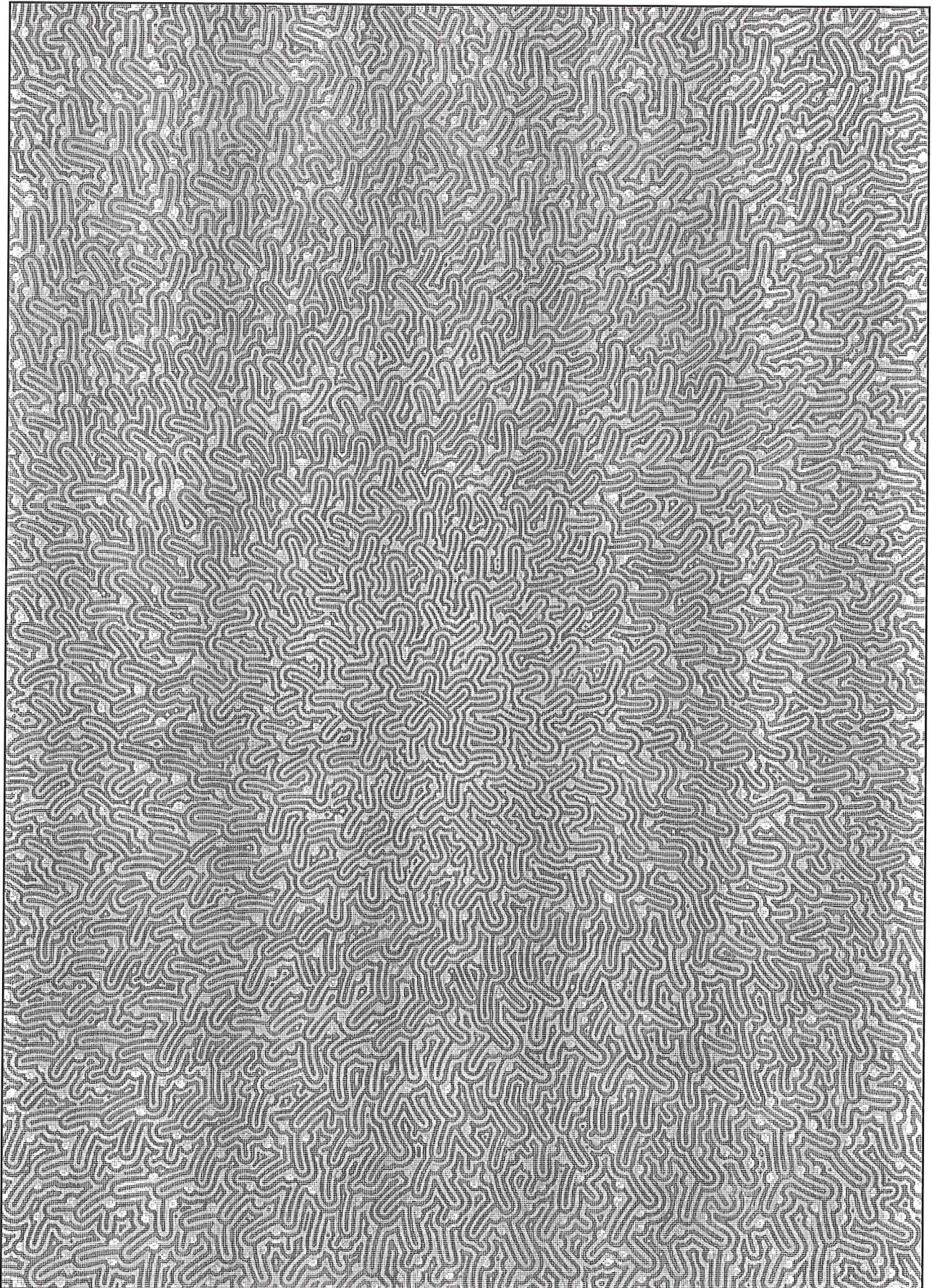
Illustration by George Cox



Artwork by Michael and Cathy Byrne which was exhibited at the *Art and autism* exhibition earlier this year and was also featured on the cover of *Asperger United* (see edition no. 20).



Flowers
by Sue Norris



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