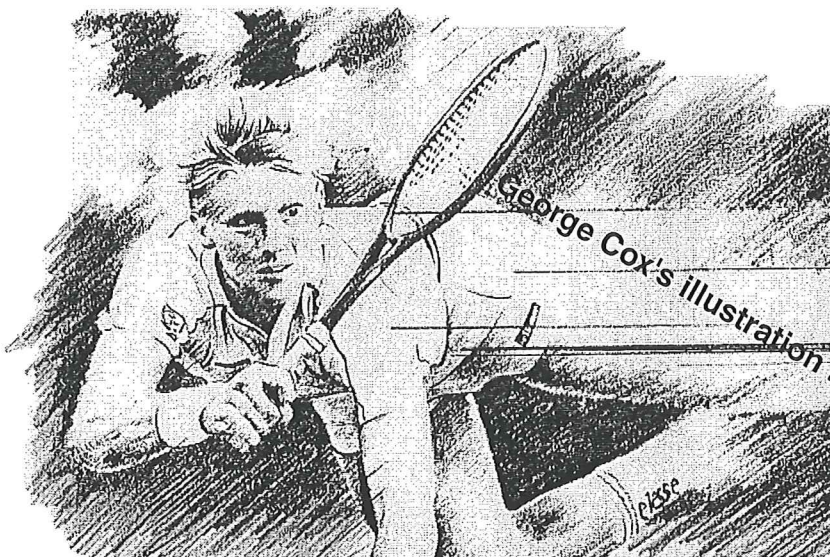


Produced by and for people with autism and Asperger syndrome

# *united* Asperger

No 19 Winter, 1999

## New design for '99!



**Calling all budding artists –** If you would like to try your hand at doing an illustration please send them into the newsletter. We hope to use any illustrations on future covers of Asperger United.

Asperger United has (again!) been updated, redesigned and even printed as a new start to 1999. We hope you enjoy this issue, and the improved quality, of the newsletter.

## Also in this issue...

- Regular News • Letters to the Editor • Pen Pal Network
- Features • Talent Scout section • Poems





# **Asperger** *united*

*Asperger United* is a self-help newsletter run by and for people with Asperger syndrome. Its aim is 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

## **Subscriptions**

Annual subscription: £4 (4 issues per year).

Please make cheques payable to: The National Autistic Society

**Please send all  
correspondence to**

*Asperger United*

c/o The National Autistic Society

393 City Road

London EC1V 1NG

**Fax:** 0171 833 9666

**For all enquiries about *Asperger United***

Telephone: 0171 903 3557

Thank you to George Cox who kindly produced the front cover illustration and those used in the Pen Pal Network and Talent Scout sections.

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 assisting in the publication of the newsletter.



## Dear Readers,

Welcome to the first edition of the newsletter for 1999 and a Happy New Year to you all. Many thanks to all who have contributed to, and ensured the production of, the magazine.

Since the last edition, I have changed my work situation. The main purpose of my job is to now store work for colleagues who have just moved from our main offices. This is to allow for refurbishment and a new computer system to be installed.

I sent Christmas greetings all over the world and news of my replies are printed in the News section on page 4

I also received a reply from Autisme Europe regarding my suggestion to include Asperger syndrome on the agenda for the IAEE 6th International Congress to be held in Glasgow, in May 2000. My suggestion has been submitted to the Congress' Programme Committee and I am awaiting their decision. Hopefully, I will be able to report further news of this in the next edition of the newsletter.

The newsletter would welcome contributions from as many readers as possible on all subjects.

Subjects could include:

- holidays
- interests
- sports
- gardening
- cooking

On page 5, I have written an article on my holiday in France, which I hope you will find of interest.

Enough for now.

Your Editor,  
*John Joyce*

## WANTED – Contributions for the next edition

The National Autistic Society's Autism Awareness Week runs from the 1 – 8 May this year and will focus on issues surrounding diagnosis. The next edition of *Asperger United* will be out shortly after the awareness week and, to follow on from the week, we hope to dedicate the next edition of *Asperger United* to issues surrounding diagnosis. We hope that you will send us contributions on the subject of diagnosis. We would like to receive any contributions: personal accounts of getting a diagnosis, how you felt about being diagnosed, how you the diagnosis has helped you, and other issues you would like to raise.

We look forward to receiving your articles.



**Editorial 3**



**News 4**

**Pen Pal Network 11**

**Letters to the Editor 8**



**Feature 9**  
An account of what it feels like to be autistic

**Talent Scout 12**

## contents

## Government replies to enquiry about travel concessions

A copy of the reply to John Joyce's letter has been copied below for your information (and use if you are in a London authority and not already receiving travel concessions). John Joyce will approach the Minister of Transport again on your behalf, expressing dissatisfaction with the fact that concessionary fare schemes are discretionary as this severely limits the life of people whose life is already difficult and limited in other respects.

Dear Mr Joyce,

Thank you for your letter of 3 November to the Deputy Prime Minister, concerning travel concessions for disabled people. I have been asked to reply.

As the law stands at present, concessionary fares in London and outside are very much a matter for local discretion. Local authorities make their own decisions on what concessionary fare scheme to provide, in the light of their judgement of local needs and circumstance and their overall financial priorities. In London however, all 33 local authorities have to reach agreement over the concessions offered. The present scheme provides free travel to elderly, blind and disabled people on buses, the Underground, and train services within Greater London.

I suggest that you contact your local authority direct to enquire as to your eligibility.

Yours sincerely,

Mr S Chester  
LTD 1 (Buses)  
Government Office for London  
New London Governance Directorate  
2nd Floor, Riverwalk House  
157-161 Millbank  
London SW1P 4RR

### Note from the editors

For those readers who are planning to apply for a bus pass or are having some problems obtaining one from your local authority, Anthony Cresswell's letter on page 8 will be of interest.

## New email list

An email list similar to *autism-uk* has recently been set up. The new list is called: *AAA: Autistic Adolescents and Adults*.

AAA aims to provide parents, of older children with autistic spectrum disorders, a place to talk about issues specific to them. Most of the existing lists are dominated by parents of young children, and deal with much different issues to those of parents with older children.

If the list becomes very large it may be split, and there are some tentative plans to have a list specifically for individuals with Asperger syndrome, and higher functioning individuals with autism.

However, at present even though the list is primarily for parents, people with Asperger syndrome and autism are more than welcome to subscribe, as their experiences of transition, employment and living independently, will be particularly relevant and useful to parents using the list.

Individuals wanting to subscribe to the list should send an email to:  
[klbuckle@email.msn.com](mailto:klbuckle@email.msn.com)

## Correction to webpage address

Thank you to Laura Clayton who noticed a mistake in the last edition of *Asperger United*. We listed the IRC channel #asperger but gave the old webpage address. The new address is: <http://www.invl.demon.nl/irc.asperger>

This address has much more up to date information on the channel, including details of a recent move to the StarLink-IRC server.



## My holiday and annual pilgrimage in France

by John Joyce

In August 1998, I arrived at Oustreham, Normandy, which is the port of Caen. The start of my holiday in France was spent attending an Open University Summer School at the University in Caen. Formal classes were held each morning and during one class we walked part of the city attempting to answer a set of questions, about various sites, in French. On another occasion we were sent out to familiarise ourselves with the city of Caen's geography and history by visiting museums and public buildings.

After the course and on from Caen, I travelled to Nantes and then on to Bordeaux. I stayed in Bordeaux for two nights, visiting many churches, before moving on to Toulouse. My main preoccupation in Toulouse was visiting the many churches and attending early morning mass, held in a side chapel of the City's cathedral. From Toulouse I moved on to Lourdes.

Every year since 1981 I have attended a pilgrimage to Lourdes as a member of a relatively small group representing the Roman Catholic diocese of Southwark, covering the counties of South London (ie south of the Thames river) and Kent. Many thousands of people make the pilgrimage to Lourdes every year during the period of Easter to October. The Southwark Diocesan group is part of a larger English group

### The annual pilgrimage to Lourdes

The pilgrimage traces its origins to 11 February 1854 when, in Lourdes, Bernadeth Saubirous, and two younger relatives saw a bright light on the bank of the river and a woman appeared to them. The woman who appeared to them was the Holy Mary, who they then prayed with. This was the first of eighteen apparitions which ended on 16 July of the same year. Pilgrims started to visit Lourdes after word of the apparitions had spread and now people from all over the world make the annual pilgrimage to Lourdes.

who make the pilgrimage annually. Within this larger group we have distinct groups of helpers: doctors and nurses, who attend the pilgrimage on a 'busman's holiday, doing their everyday work for free; nursing staff, who help the sick pilgrims at meals and going to and from church services, and marshals. My main responsibility – as a 'bridge marshal' –, was to direct 'traffic' (ie. wheelchairs) to church services. I occasionally pushed wheelchairs or helped to carry 'voitures' – a large chair used to carry someone who does not have a wheelchair – to church services and the shops.

## Greetings from around the world

*Asperger United* received Christmas greetings and wishes for a Happy New Year from organisations from around the world.

Greetings were received from: Krajowe Towarzystwo Autyzmu, a Polish organisation, APPDA, a Portugese organisation, and Action for Autism in India.

## The National Association of Care of Autistics (NACA), in Tanzania

First of all I should say I am sorry for not having replied to your last letter, which included a copy of *Asperger United*. Secondly, I should thank you for the trouble you took to write to me – I really appreciate it.

I should give you a brief history of how I started our association. In 1990, I received a scholarship for further studies in Ireland at the Stewart Institute where I studied mental handicap, geriatric nursing and child/adolescent psychiatry for one year. After completion of the course I returned to Tanzania and worked with an Irish doctor, who was a child psychiatrist, and whilst running our clinic we identified that there were children who were autistic. We consulted the children's parents and, with them, started a parent's pressure group in order to lobby Government for a special unit for the children. We were told that the Government did not have any funds for a special unit. However, we went back again and again to the Government, and specifically the Ministry of Education, who then decided to give funding for six teachers, one of whom was trained. I had to work tirelessly in then getting financial assistance for the other teachers to go on a three week course about autism.

I do all I can to help members of our association. I am not paid and our parents members are poor. I am their co-ordinator and often use my own money although I am not paid much in my real job as a Nursing Sister in our National Hospital.

However, the unit is now up and running.

Jane Mwenda



## ABOUT THE NATIONAL AUTISTIC SOCIETY

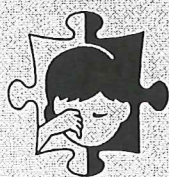
The National Autistic Society (NAS) was formed in 1962 on the initiative of a group of parents who were later joined by professionally interested people. Today, the Society has grown into the UK's foremost charity for people with autistic spectrum disorders and those who care for them, spearheading national and international initiatives and providing a strong voice for autism. The organisation works in many areas to help people with autistic spectrum disorders live their lives with as much independence as possible.

### The NAS

- runs education and adult centres
- supports local authorities in the development of their own specialist services
- publishes a range of books and leaflets
- has a library that parents and researchers can use by appointment
- runs an autism helpline for parents and carers and people with autistic spectrum disorders
- organises conferences and training programmes
- co-ordinates the work of volunteers on nationwide parent to parent and befriending schemes
- offers specialist diagnosis and assessment services
- encourages research into the causes of autism
- supports local groups and families around the country
- raises awareness and creates a better understanding of autism
- provides consultancy to professionals and organisations working in the field of autism
- offers an accreditation programme for autism-specific education and care services
- runs Prospects, a supported employment service for adults with autistic spectrum disorders.



**Asperger United**  
c/o The National  
Autistic Society  
393 City Road  
London EC1V 1NG



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E-mail: [nas@nas.org.uk](mailto:nas@nas.org.uk)  
Web site:  
<http://www.oneworld.org/autism-uk/>

**The NAS in Scotland**  
Suite 3, 111 Union Street  
Glasgow  
Strathclyde G1 3TA  
Tel: 0141 221 8090  
Fax: 0141 221 8118

**The NAS in Wales**  
William Knox House, Suite C1  
Britannic Way, Llandarcy  
Neath  
West Glamorgan SA10 6EL  
Tel: 01792 815915  
Fax: 01792 815911

### Services Division - for details of NAS schools and adult centres

Church House  
Church Road  
Filton  
Bristol  
BS34 7BD  
Tel: 0117 987 2575  
Fax: 0117 987 2576

### Development and Outreach and Training

Castle Heights  
4th Floor  
72 Maid Marian Way  
Nottingham  
NG1 6BJ  
Tel: 0115 911 3360  
Fax: 0115 911 2259

### The NAS Centre for Social and Communication Disorders

Elliot House  
113 Masons Hill  
Bromley  
Kent  
BR2 9HT  
Tel: 0181 466 0098  
Fax: 0181 466 0118

# How to reply to Pen Pals



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

If you would like to reply to any of the letters then please send your letter to:  
**Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.**

We will pass your letters on to the appropriate person. However, we cannot guarantee the person will reply as that is entirely their decision.



## **Bruce Hateman Stevenage, Hertfordshire**

My name is Bruce Hateman. I am Male, 37 and I have Asperger syndrome and looking for male and female Asperger pen pals - possibly friendship.

I am a bit of a gentleman/anarchist. I write imaginative children's stories. I am a great Dr Who fan (Patrick Troughton - Jon Pertwee era). I am doing a Chemistry and Biology Course (for slow people) and I am also a bit Occult (Aleister Crowley - but not the weirdo sexual stuff) more Crowley/chemist/with a touch of Celtic lore. Love King Arthur legends, Giants and things ..... plus old Castles!

I am unemployable and would rather not talk too much about work - but if you're a mega intellectual, weirdo individualist, or an assertive lady left on the shelf, you'll probably find me a good friend. Like the Doctor, I am something of an eccentric!! Who wants to be conventional?

## **Anthony Cresswell, Nottingham**

My name is Anthony Cresswell and I am 26 years old. I live in Nottingham and was diagnosed with Asperger syndrome a year ago. I am on incapacity benefit because I get depressed due to my impairment in social and occupational functioning.

I attend the Theonoptical Hall and I have interests in Theonophy. The Western Mystery tradition Esoteric pursuits and spiritual growth. I practice transmission meditation and healing. I hope this does not sound heavy for some readers and puts them off writing to me. I also enjoy music like New Age, Folk, Blues and most soft/heavy metal. Some of my favourite groups are Steeleye Span, Heart, Vixen, Bonnie Tyler, Eric Clapton and Guns 'n' Roses. I enjoy a meal and a few pints in a pub and would like to expand my social life. I keep fit and have become a blood donor. I am thinking about becoming a Samaritan or doing some work for charity - the NSPCC is a charity that comes to mind. I hope that I will get a response to this request for pen pals. It's nice to hear from other people with Asperger syndrome.

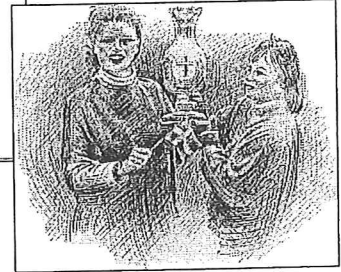
## **Stephen McCarthy, Romford, Essex**

My name is Stephen. Some of you know me, as I attended the Mauldsley Social Skills Group a while back. My story and poetry I've also asked to be included within the newsletter. My interests include Music and Religion. I would like to hear from anyone, male or female, especially if they live near me. I am 33 and suffer from Asperger syndrome rather than autism.



Illustrations by George Cox





# Poems

Four poems by Stephen McCarthy

## Bonker Boy Banana's

Bonker Boy Banana's  
In his striped pyjamas  
Tossing and turning all around

Bonker Boy Banana's  
In his striped pyjamas  
Fell and hit his head upon the ground

Bonker Boy Banana's  
With the striped pyjamas  
Now he is not normal anymore

Bonker Boy Banana's  
With the striped pyjamas  
For he is abnormal to the core.

Stephen McCarthy

## Cat and Mouse

The cat and mouse were in the house  
Running round the table  
The cat it reeled, the mouse it squealed  
And in came Auntie Mable

Stephen McCarthy

## The Zoo

Cheeky monkey at the zoo  
Made funny noises ooh, ooh, ooh  
Bill Goat and Kangaroo  
Laughed until they were both blue

Liam Leopard lost his spots  
Bryan Lion then roared lots  
Croc O'Dile he gave a smile  
One so big it spanned a mile

Chee Tah played a trick or two  
Things were madness at the zoo

Stephen McCarthy

## Fatty Patty

Fatty Patty was so fat  
She looked just like a tank  
She wore a sign that said "Give Way"  
And when she swam she sank

Stephen McCarthy

... and a poem by  
Simon Harrington

## The Rude Boy

"Here he comes" echoed the voices of  
the children

The object of their attention was me.  
I kept my eyes fixed on the double  
doors that lead to my freedom.

"He thinks he's too good to speak  
with us" one child said.

Deep in my mind a sarcastic remark  
surfaces

But was soon consumed by the fear I  
was feeling.

I really would have loved to stand and  
chat, only for

them to taunt me more I'm sure  
However I remained stone and  
continued on.

Then one of the children block my  
path

"Lost your tongue dummy" he  
laughed.

Soon the others were laughing too.  
I felt the rage of all the abuse I had  
suffered well up inside of me.

A tear trickled down my eye.

My emotions were now on show.

Through all this turbulence I felt

I kept my mind on the double doors.

And with a slight nudge the child

Blocking my way moved and I  
continued on.

Knowing only too well that my  
Tormentors would be there tomorrow  
as well.





## letters to the editor

Please send all letters to: **Asperger United**, c/o The National Autistic Society,  
393 City Road, London EC1V 1NG. Fax 0171 833 9666

### 'Writing started off as a crutch I could lean on when times got rough'

Dear Asperger United,

My name is Simon and a few months ago I was diagnosed with suffering from Asperger syndrome. I know I said 'suffering', but in a sense I felt a great relief upon being diagnosed.

You see, for years I had merely rambled through life, being passed from one Doctor to the next in an effort to find out what was wrong with me. Some of the Doctors put it down to nervous tension, others hinted at emotional problems, but none of them could ever give my parents a clear answer, which led to a lot of emotional turmoil for them both. The only really good thing that emerges from the trauma I suffered from not knowing what was wrong with me, was that I became a writer.

Writing started off as a crutch I could lean on when times got rough. It was a safe sanctuary I could withdraw myself into from the world that I found so strange. I even had the good fortune to become involved in a charity project for The Samaritans, where I donated the proceeds of a book they helped me print. You see I am not in writing for the money. It is more my way of communicating with the world I cannot seem to understand. So if there is anyone out there who requires something written for an Asperger syndrome charity I would be more than willing to help. Also, if there are any Amateur Dramatic Groups seeking a play to perform - I have already written a play which is waiting to be performed.

I suppose like so many other Aspergers I am looking for an outlet to express myself and I believe I have found mine in writing. I just hope all my fellow sufferers will find there outlet.

Yours faithfully,  
**Simon Harrington**

#### Reply from the editors

Thank you for your letter Simon. We are pleased you have found an outlet for the suffering you have felt. We understand you have been asked to write an article about your experiences for The National Autistic Society's Website. This is excellent news.

### Improve the leaflets

Dear Asperger United,

Asperger syndrome is different from other disabilities because most people who are not sufferers do all or most of the things mentioned in leaflets about Asperger syndrome, but people with Asperger syndrome do them more often, so it appears to be a question of degree rather than a real difference. I wish that leaflets about Asperger syndrome would explain this in so many words instead of making out that Asperger sufferers are a different kind of species.

As everybody who has Asperger syndrome is born with it and does not develop it later in life it is very difficult to know what a sufferer with Asperger syndrome would be like without it. I suppose I would still be persistent but would I be able to convince people more easily that what I was saying is not my obsession but logical.

I was disappointed that my point which I made at the Maudsley conference was not dealt with. I

would still like to know if being persistent is Asperger syndrome. Sometimes it is good to be persistent even if it makes you unpopular. I would also like to say that there are times when I was right about what other people are thinking and people were wrong.

Leaflets on Asperger syndrome are 'better than nothing' as they give some idea about the condition, although by exaggerating we are set apart. Leaflets should also stress the point that when communicating with someone with Asperger syndrome people should express themselves clearly and unambiguously which would make things easier for us sufferers, and also non-sufferers, to know what they are saying and thinking.

I took part last summer in research at the Maudsley, hoping it would help them to change the leaflets.

**David Shamash.**



## Secretin, and a repsonse to Philip Hill, in Edition 18

Dear *Asperger United*,

I was interested to read of the hormone Secretin and its effects on children with autism. Secretin is used for gastrointestinal problems. It was back in 1995, during Psychotherapy, when I was told about the connection between the gut and the brain/mind. I was told that the gut and the brain/ mind are linked in such a way that you can tell how they were functioning together. As a 'block' in the mind would account for blocked bowels and vice-versa.

It is known that high anxiety and Irritable Bowel Syndrome are connected. Secretin must also then work on the temporal lobe of the brain. It is here where thought and feelings are processed, and problems occur in the temporal lobe in autistic spectrum disorders.

Hopefully in the future, Secretin will be available to all in the UK and will be beneficial to Aspergers folk too.

Also, can anyone explain what was meant, in edition 18 (pg 9) of *Asperger United*, by Mr Philip Hill in his letter, as to certain characteristic 'eyes' or 'hair' in folk with Asperger syndrome? I feel that I have Asperger syndrome but have not been diagnosed and perhaps I have typical 'eyes or hair' that could help in my diagnosis. Please write to *Asperger United* with your answers, whom I hope will pass these on to me.

Happy New Year to all.

Tom Lee

### Reply from the editors

Thank you for your letter Tom. In our next issue we will provide some information on the subject of Secretin and gastro-intestinal problems in autism. Hopefully this will answer some of your, and our other readers, questions.

The answer to your questions about the possibility of there being

a typical hair and eye characteristic in Asperger syndrome is two-fold. Firstly, that this will not help in your diagnosis, as a diagnosis should be made on the basis of the fundamental characteristics of autism/Asperger syndrome being present (ie. social/communication/ imagination deficits). This should be established by a professional through an interview with yourself and a person who would be able to give an account of your early developmental history. Secondly, it is not uncommon to see other features such as unusual hair patterns, problems with eyesight in people with Asperger syndrome. This is not however a diagnostic feature as similar hair patterns and problems with eyesight can be seen in people with other disorders as well.

Thank you for your best wishes.

## The River of Life

Dear *Asperger United*,

I have wanted to do something worthwhile to help my fellow brothers and sisters. I feel compassion for the sick and needed to do something to help the sick and suffering. I pray on a daily basis for the healing light to touch the sick and suffering. I believe in the power of prayer but wanted to do more. It's one thing feeling compassion for the sick and suffering and praying about it, but it's another thing actually getting up from your armchair and doing something more about it.

I did not know what to do and one

day I went to the City Centre of Nottingham and I came across a road traffic accident. The road had been closed by the Police and a crowd had gathered at the incident. I was anxious that people had been badly injured or killed, I could not see any ambulances and I got closer to the accident to see if I could help by giving first-aid. I soon realised that the ambulances had already taken the injured away. I could see before me a river of blood and thought someone must have been very badly hurt. I prayed that the ambulances arrived swiftly to the RTA and ferried the injured to the Accident and

Emergency department in time. I stood on the corner of this accident hot spot looking at the river of blood, I prayed that the injured would be saved and then I realised that I would become a blood donor. I was happy that I was shown a way to help the sick and I have now donated a pint of my blood. I will continue to donate blood and recommend others reading this will also help save a life. It is a wonderful thing to do for other people and the thought after you have donated is that of knowing you have helped save a life.

Anthony Cresswell





## letters to the editor

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393 City Road, London EC1V 1NG. Fax 0171 833 9666

### In response to Philip Hill, in Edition 18

Dear *Asperger United*,

I read with great interest Philip Hill's response in the last edition, to my letter in edition 17 of *Asperger United*. I have the following comments in response to Philip Hill.

The group psychotherapy, with non-Asperger women and men, I attempted was of the Gestalt School of psychotherapy which is very confrontational. I got very upset at being forced to express my feelings and emotions to order, and yet when I did the group did not like it and so I had to stop. People with Asperger syndrome may not usually express feelings and emotions well and then they may suddenly over-express themselves. I believe trials were carried out in the States, with regards to people with Asperger syndrome in psychotherapy groups, which came to negative conclusions.

The Mary Lynch Group to which I belong does include psychodrama. Psychodrama allows you to get in touch with, and by 'honest acting', help you to re-enact suppressed emotions, with due control. We may also, in private sessions, do Freudian and Jungian analysis which I do find of help. I believe and agree with Philip Hill on analysis as I can 'free associate' (Freud) all my honest feelings, even socially unacceptable ones however absurd, which according to Freud and Jung surface from the subconscious, without feeling ashamed. Yes, it takes a lot of commitment but nothing good comes cheap.

It is also interesting to note Jung

on the 'introvert' and the 'extrovert'. The introvert (though often not as is often misunderstood as anti-social) gets his resources/ inspiration from 'inside' and the extrovert from 'outside' and from others advice etc. I'll leave that for you to draw your own conclusions. I know I prefer to do things my own way - including my career, home, business, personal relationships - as difficult as they can be. I will say that Gestalt could well be suitable

for the non-Aspergic, Jungian 'extrovert' as advice from others is given.

Personally, I can only conclude with the Bismarck prayer, 'God preserve me from my friends, my enemies I can deal with alone'. Thank you to Philip Hill for his response.

Yours sincerely,

**Tim Loder**

---

### In response to the recent debate about bus passes for people with Asperger syndrome

Dear *Asperger United*,

I have noticed that the subject of bus passes has been a theme of the newsletter recently and that there is some confusion surrounding this topic because some people with Asperger syndrome are getting passes and others are not. It is a true statement which the editor gave in Edition 17, that people with Asperger syndrome are entitled to bus passes but need to say the relevant things in order to get one. I have recently got my bus pass because one of the characteristics of Asperger syndrome is motor clumsiness and I said because of this I would not be given a licence to drive. Also, I said that I take anti-depressants and the side effects of

which could cause drowsiness - a driver who could nod-off whilst driving is dangerous. I was also surprised that the GP agreed and also ticked another box to indicate I was handicapped. The GP considered Asperger syndrome a handicap which I thought was somebody in a wheelchair or something. The GP said that some people are physically disabled and others are mentally disabled - but both are conditions which can hamper or hinder.

**Anthony Cresswell**



# An account of what it feels like to be autistic

by Debbie Hudson

On Friday 30 October 1998, I went with my mother to see Dr Brugha who is a Psychiatrist. He specialises in autism and Asperger syndrome. My mother talked to him for two hours. She told him about my whole life from birth up to the present day. As she was talking to Dr Brugha she felt so relieved because this was the first time that anybody had listened to her. Dr Brugha said that in assessing the actual person, you have to talk to the parent. Eventually, he diagnosed me as having Asperger syndrome, which is a mild form of autism.

My mother and I were so relieved, a huge weight lifted off us both. I burst into tears and I felt as though I had been reborn. My mother was able to iterate all her instincts to fight for me for 35 years. She wondered whether her motherly instinct as well as knowledge made her so certain. My mother felt that at last she had won the fight after 35 years.

I now realise that Asperger syndrome affects children and adults in different ways.

It is for this reason that I have decided to write an account of what it feels like to be autistic. I want to educate people and make them understand. I do not want other children and adults to go through what I went through because of a very late diagnosis.

## The importance of an early diagnosis

I went through much pain and suffering, all because I was diagnosed very late. Until ten years ago, only the children who had very bad autism were recognised. Able autistic children, such as myself, were excluded from a diagnosis and subsequent help.

## These are the ways in which autism affects me:

- › I want to be sociable but I often feel isolated.
- › I am physically clumsy.
- › I have problems expressing myself and interpreting communication.
- › I have good vocabulary but I often interpret words and phrases literally.
- › I have poor self awareness in group situations. I do not respond to instructions for the whole group. I require individual instruction and I learn best from one to one teaching, monitoring and review. I need straight forward instructions. I have difficulty remembering instructions and can follow them when broken down into stages. The memories may be stored but not accessible. I need to be taught everything systematically. I am not able to use common sense, even though I am not stupid, and I cannot be expected to just pick things up.
- › I am verbose and become unclear and muddled about what I am saying, often going off at a tangent and not keeping to the point.
- › I may panic in a new situation and have a high level of anxiety and resultant stress.
- › I interrupt and I may butt in on conversations because I have difficulty in knowing when people have finished speaking. Also, I may butt in on conversations which have nothing to do with me.
- › I find handwriting difficult. I had to have writing lessons at school.
- › I have a detailed memory for past events which other members of the family have long since forgotten.
- › I under perform at school.
- › I am a super reader.
- › I do not know when someone is being sarcastic or when they are joking.
- › I cannot cope with crowds like assembly or parties.
- › I have difficulty making friends of my own age.
- › I am single minded.
- › I cannot function if there are too many changes in the day.
- › I can do some things very well, quickly, but not tasks involving social understanding.
- › I fail to realise the effect my odd behaviour has on others.
- › I sometimes forget to look in the mirror to see if I look all right.
- › I sometimes do my buttons up wrong.
- › I can only do one thing at a time.
- › I have a habit of staring, but I am trying to get out of it.

The importance of early diagnosis is crucial. If the child is diagnosed early, he/she will not have to go through the years of suffering I went through.

To those of you who work in the Autistic Societies, I hope my account

will help you to help others. To those of you who work in other medical fields such as child psychiatry etc, please take my account seriously.

I hope my account of what it feels like to be autistic is interesting and thought provoking.