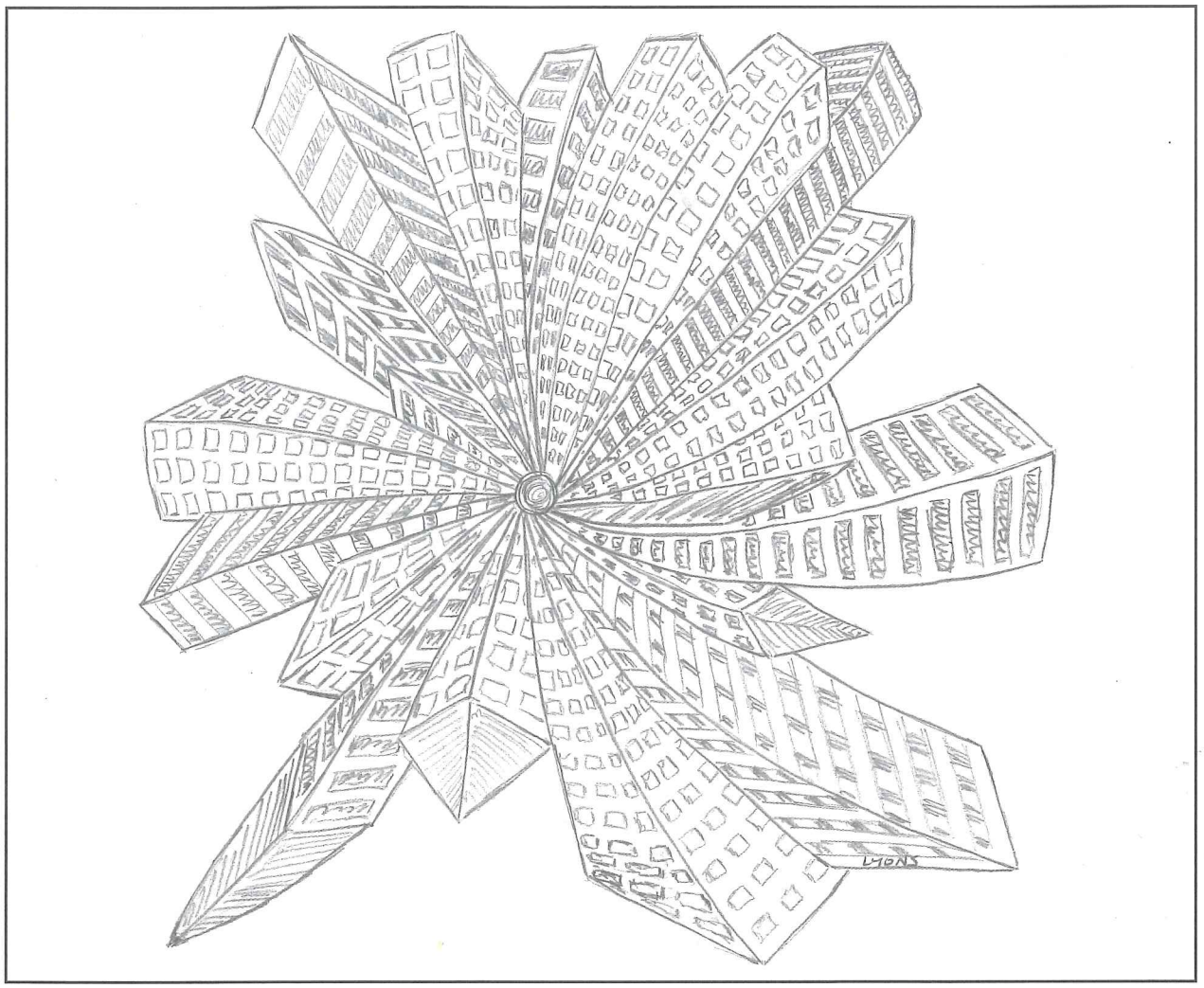
Produced by and for people with Asperger syndrome

Asperger united

Edition 41 January 05



'Shopping' by Sara Lyons

The National Autistic Society

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.*

Contributions for the next isssue should reach us by
20th February 2005

Asperger United was founded in 1993 by Pamela Yates and Patricia Howlin, in association with the Maudsley Hospital, and Mark Bebbington and Judy Lynch of The National Autistic Society.

This was in response to a recognised dearth of services for people with Asperger syndrome and the potential for self help and networking as a means of support for this group.

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds and the current editor, John Joyce.

Pamela Yates provided support and advice to the editors until the publication was handed over to The National Autistic Society in 2000.

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

Dear readers

Happy New Year! Hope all is well with you.

May I take this opportunity to thank all who have contributed to the success of our paper during my editorship and our friends at the National Autistic Society for the printing and distribution of the magazine. Please keep those contributions coming in.

A number of us were guests of a Member of Parliament in December. A report will be prepared for the next edition.

I thought it might be amusing for some to hear of a recent visit of mine to the city of Cambridge. Having watched Histon Football Club be defeated by Yeovil Town in the FA Cup, I made my way to the church of Our Lady and the English Martyrs for the Evening Mass. On my way I saw buildings for sale by the appropriately named firm of 'Bidwell'.

Best wishes from your editor
John Joyce

in this edition

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Catching up with an old friend - Peter Myers

Dear *Asperger United*

Hi and best wishes to John Joyce on his 60th birthday. I met John briefly, after the conference at the Institute of Psychiatry in September and he seemed a splendid chap.

Anna Cohen, who suggested the name *Asperger United*, also introduced herself to me. It was a pleasure to meet them both

Usually I am quite quiet and shy and do not approach people. However, if I do start talking, it may be difficult to shut me up. It is just that I am reliant on others to take the initiative, and I always prefer one to one social interaction, as groups sort of swamp, overwhelm, engulf my senses and confuse me.

The conference itself was most interesting and usually I like to just listen to the knowledge and experience of others. And it is nice to be in that environment of 'metaphorical kin'.

Lorna Wing mentioned in her talk Dr Sucherawa from the former USSR, who published a paper concerning a group of children who were virtually the same as those Asperger described. However it was Asperger whose name came to define the syndrome. I found this new information fascinating and if anyone knows any more about Dr Ssucharawa and her work, I would be most interested.

I haven't written to *AU* for a while, but I know that readers are interested in those doing courses at college. I work at Remploy in York and, with their assistance and support, I am doing an Arts foundation course (Diploma level, part time over 2 years) at York College.

I love art and I like artists – they seem an off-beat, colourful bunch of crazy eccentrics (in the nicest possible way) like myself.

Since last September I have been hard at work doing a variety of college projects. Initially students did some twig and ink drawings outside (literally finding a twig and things outside to draw and paint with). Students also did some collage work, 'still life' and some figure drawing (drawing people I find difficult).

Then students started their first project – fashion/textiles. One had to select a garment, deconstruct it and then put it back together in a new form. In this respect it is similar to the process of abstraction, yet in a literal sort of way. I chose a man's shirt, which I transformed into a piece of sculpture, with my theme of 'What is this fashion thing anyway?' The next project was 'mummified technology' which was similar, as students had to dismember a piece of modern technology to create an art piece.

One of the many things I've done is an updated version of a picture I had originally drawn in 1979, during a period of depression. Although I am long recovered from this, I just thought that I could use these powerful images as part of my more recent artwork.

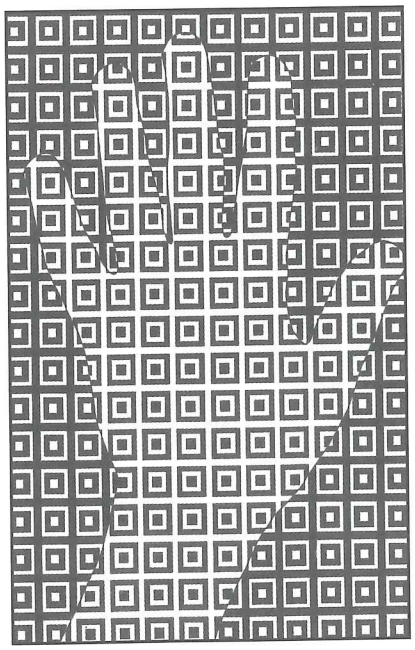
I can now look back on that unhappy period of my life from a safe distance, objectively. So I have no hang-ups about that. Yet I can constructively re-examine that period of my life objectively in my artwork, and may produce something of important value, something useful out of that chaos.

Also as part of our study, we attended a series of Art History lectures. The project set for art history was an essay based on the artist or designer who had most influenced our work. I struggled with that essay for sometime before I realised my difficulty. I considered the question presumptuous as I did not think I had been (at least not consciously) influenced by anyone. So I thought about what most influenced my work and wrote my essay on 'Asperger syndrome and how this and art influences me'.

For this second and final year of study, I am specializing in Fine Art, which is an area that interests me. Students' initial project is entitled 'Internal, external, eternal'. I have now nearly completed a hand sculpture for this (I like hands). I may continue this theme through-out the year, focusing on 'Internal' - internal states (depression, autism etc) stemming from my own experiences. I hope it will be interesting.

Best wishes

Peter



Dear AU

I was very interested in Jeremy Field's article in the October 2004 issue of *Asperger United*, particularly his obsession with railways.

Let me tell you a little about my own experiences. I am in my late fifties and was diagnosed with Asperger's only a few months ago. I have been married for 34 years. My wife and I have had plenty of problems over the years, most of which in hindsight we can put down to Asperger's. It is entirely thanks to my wife, who saw an article in the *Daily Mail* in 2003, that we now know who the real 'enemy' is. We are having some counselling, but are disappointed that there seem to be so few specialists in this area.

Why do so many 'Aspies' have an obsession about railways? I think that it is part of our desire to seek order out of chaos. Society can be very confusing. We tend to take things literally, and are often thrown (oops! not literally!) when we discover that people do not always say what they mean or mean what they say. Body language is sometimes baffling: it can alter the meaning of what is being said. If we do not pick up on the body language, we end up misinterpreting the person's meaning, with all sorts of repercussions. There are so many twists, turns and nuances to communication that we feel like giving up altogether!

So: what is the connection between this and railways?

Railways are orderly. They create order out of chaos. Trains run on a guided track: if the line curves to the left, the train goes to the left. Complex interlocking of points and signals means that, if a train is signalled to divert to the right, and the line is clear, the train will indeed go to the right, and it will keep out of the way of every other train. Trains usually run to a fixed timetable. Everyone - customers, passengers, operators and engineers - knows where every locomotive, carriage and wagon will be at any particular time, where it has come from and where it will be going. If only life were a bit more like that!

From my earliest childhood I was interested in railways. I was never a 'trainspotter': I never collected engine numbers. But I enjoyed going down to my local station after school and admiring the orderly way in which everything was done. In a strange sort of way, it felt 'safe'.

I wonder if that was what attracted me to the railways as a career. On graduating from university I joined British Rail as a management trainee, and pursued a career in operations, planning, consultancy and computing, until I took early retirement following redundancy a few years ago, since when I have worked freelance. My achievements have been fairly modest, and I am sure I would have done better if I had had the networking and interpersonal skills that neurotypical people have. One of my most satisfying jobs was in the late 1970s when I worked on timetable planning on southern commuter services. (Yes, you can blame me!) It was the ordered, logical way in which you had to do things, and the tremendous attention to detail, that appealed.

I mentioned computing – another Aspie favourite. Computers are logical beasts. They may infuriate us at times, but if you understand the rules you will know that if something goes wrong it is always your fault, never theirs. Computers cannot get things wrong. They do exactly what you tell them to do. They take things literally! We Aspies understand that, which is why we feel comfortable with them.

Computers have been part of my life for over thirty years, and I love them to bits!

John Ray

Dear *Asperger United*

Since I started receiving *AU*, articles and contributions from other sufferers have greatly encouraged me as I have seen my own little 'odd-ities' described by other contributors, and it really does 'unite' us to read articles that describe the very things that we struggle with.

As you know, some people suffer more in certain areas more than others, but to see in print by another contributor the very things I suffer from, makes me feel less an 'oddity' and more like someone who belongs to a very special group of very special people – the Asperger community.

Keep up the good work. You are doing a wonderful job of uniting people with AS, and making them feel less isolated and more accepting of themselves.

Thank you so much for the lifeline that *AU* provides
Sue C

I'm Basil. I am 26. I was diagnosed with AS in 2004 and I'm still learning about how it affects my life. I am interested in hearing from people with AS who are of North African, Middle Eastern and Muslims of South Asian origin. I think that AS can be mixed with social, family, cultural and religious issues so it can be harder to identify because there could be many factors related to AS.

Hi! my name is Sean. I am 19 and I have AS. My interests are music, in particular, Queen. I also like drawing, art and food. I would like to hear from somebody who, like me, needs a network of support. I am very interested in forming a relationship with a female aged18-20.

letters to the editor

An open letter to Dr Lorna Wing

I was not able to attend the conference in September 2002 but I read an article about what you said with interest in the October 2004 edition of *Asperger United*. I would like to comment on two things and ask you three questions.

Firstly I cannot agree with you when you say that if everyone had Asperger syndrome it would be easier. People with the same label do not always get on. They might pursue and talk about their interests regardless of other people's wishes and as they have different interests they might quarrel a lot. If everyone had Asperger syndrome, they would be rigid and the danger is they would show no consideration for each other and quarrel a great deal.

Secondly I would agree with you if you had said before your statement that they are much more likely that 'normal' people to 'take things literally and speak the truth, regardless of what anybody else thinks or feels, and the way they pursue their special interests regardless of any other considerations often gets them into a lot of trouble.' After all, 'normal' people also do those things you mentioned but are much less likely to constantly do them than people who have Asperger syndrome or other difficulties. Are you saying that normal people do not do these things at all? ('Normal' means to me people who have not got Asperger syndrome or other difficulties) Does normal mean the same thing to you?

Lastly I would like to ask you: are people with Asperger syndrome deliberately persistent and contrary?

David Shamash

Response

Thanks to David Shamash for the issues he raised. To answer the query about what is meant by 'normal people'. As you suggest, in this context, it is usually taken to mean people without Asperger syndrome or similar condition. I prefer the term 'neurotypical' which has a nice touch of irony about it.

I had a limited time for my talk so I saved time in the way that is rather typical of 'neurotypicals'. That is, I emphasised the differences between people with Asperger syndrome and neurotypicals instead of pointing out the overlaps. I assumed the audience would take for granted that the differences are of degree and not absolute - I was wrong!

The comment that life might be easier if everyone had Asperger syndrome was a mild attempt at humour. I am sure David Shamash is right in suggesting the kinds of problems likely to be found in such a world.

The question as to whether people with Asperger syndrome are deliberately persistent and contrary is a difficult one to answer. I am sure that, mostly, they are not. The difficulty with understanding social situations and other people's thoughts and feelings accounts for their apparent contrariness and persistence in most cases. However, we are all human beings, regardless of any unusual developmental paths we may have followed, and I guess we can all get exasperated and be deliberately awkward at times. This is only a guess. It would be interesting to design a study to find out - has anyone any ideas on how to do this?

Lorna Wing

Dear Sir

Life assurance for Aspergers

I write to you because over the last year I have had many problems with the above subject. Both my daughter and my husband have Asperger syndrome and insurance companies are treating them as mental health instead of social health. Do we know how wide spread this problem is?

Maybe we could do a survey to try and establish the facts. Insurance companies have to be educated. They are making a lot of money out of us.

Please let me know if you come up with an idea.

Mrs Barnes

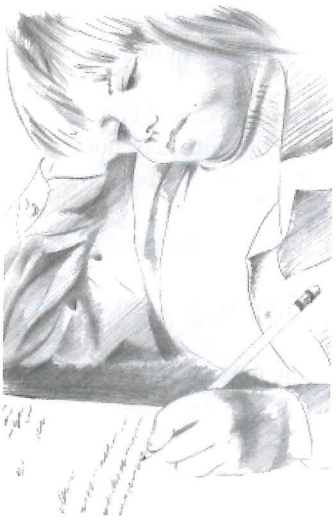
Road Traffic - advice needed

I'm the mother of a 12 year old boy, Ben, who has Asperger syndrome (recently diagnosed).

We are tearing our hair out trying to overcome the problems of road/traffic safety. Ben can tell you what needs to be done but not implement it unless the road is virtually free of traffic and it's one straight road.

Has anyone out there overcome this problem and, if so, have you any tips or advice?

Ms L Coleman



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*.

****Important notice - please read****

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

Hi, my name is George. I'm 18 yrs old and live in Kingston upon Thames. I go to college and my main interests are football, pop music, cinema and TV. I'm also learning Spanish and trying to play golf. I'm very keen to communicate with young women who have AS and are of a similar age.

Hi, my name is Osman and I am 18 years old.

I am at College studying arts media and performing arts. My interests are football, computers and computer games, reading and listening to music. I also go to acting classes which I enjoy. I would like Pen pals of either sex similar age (ages 16-19).

My name is Zoe, I am 25 and live in North Herts. I have recently been diagnosed with mild AS and am still coming to terms with the idea and learning about myself. I have recently suffered a bout of depression, anxiety and panic disorder, which I am now recovering from.

I have many interests, the main ones being collecting twentieth century ceramics and Ercol furniture, spending time with my dog, classic cars/motorbikes, the 1950s – 1970s and mental health issues.

I would like to make some new friends either as pen pals or through socializing with people in my area.

My name is Ben and I'm 12 years old*. I've recently been diagnosed with Asperger syndrome. I have no email address at the moment but will do soon. I would like to hear from other boys 11-13 with AS. I am a big Simpsons fan and I do karate and play the piano. I like going 10 pin bowling and going to the pictures.

* Parental permission given

My Asperger syndrome

Anxiety in a changing world leads to
Stress that I have to surmount.
Perception is the way I view things and
Energy is what I have in copious amounts.
Rejection is something I know much about!
Gullible I am to the amusement of others.
Endurance is my 'compensation' for my social ineptness.
Reliable oh, yes – I do what I say!

Sameness is essential as I fear change and
Yearning is wishing to join in – perhaps one day!
Naïve is what I am because I am accepting.
Different I most certainly am!
Ridicule is something I have to deal with.
Ostracised because I am different – surely difference is not a crime!
Misunderstood and very frustrated.
Empathy – and understanding – so please give me your time!

By Gaye Eastoe

Snow

Ice white flakes falling from the sky,
The cold dew turns to frost,
As the white sugar coats the mountain top.

Snowmen dressed in scarves and bobble hats,
Icicles hanging from the gutters of houses,
Sleigh rides from the top to the bottom of hills.

The white caster sugar like dust melts away,
As the river bursts its banks,
As we hear the first spring bird make its first call,
We wonder when the next snowflake will fall.

Brian Jones

Changes

My name now is Ametrine Ruth Lavender. I used to be known as Joanna Lavender.

In June this year, 2004, I was finally diagnosed with autistic spectrum disorder (ASD). I am 30 years old and have known I was on the spectrum since I was 17. In that time I have had many periods of hospitalisation as well as therapy and lots of different medications, most of which did not help me. From time to time I would mention that I thought I was on the autistic spectrum and be told I was too able. My official diagnosis was 'Personality Disorder (Unspecified)' which meant everything I said could be ignored as part of my PD.

Now I'm facing huge changes and difficulties. As with so many able ASD adults I cannot get the help I need. I currently live in short term supported accommodation where I have my own flat and there are support workers here approximately 9-5 Monday–Friday. I've been here six months already and can stay a maximum of two years. What then?

As well as ASD, again like so many others, I have secondary mental health problems. Learning Disability services won't help me and mental health won't either.

I need to live in supported housing as I often have issues I need to deal with fairly immediately to reduce risk of meltdown and/or self-injury, not to mention 'mere' extreme distress. I also have problems making necessary phone calls (eg to DSS about bills or maintenance issues) though sometimes I can do this and other times I can't for weeks at a time. When I did live on my own I was unable to flush my toilet for several weeks due to it needing a minor repair and being unable to make the phone call.

I don't make the kind of friends who could help support me, as socialising is so draining and I am awkward and uncomfortable around people where I don't know what the expectations of me are. Support workers are ok because I understand that relationship and where the boundaries are.

I don't want to live 'in the community' because there is no safety net for me there. Even if there was somewhere I could phone for help, I might be unable to make a phone call or explain myself if I did. Here I can put a written note under the door of the support worker office and know that someone will respond. My support worker says there is no long term supported accommodation anywhere for people like me. The government wants us all to live independently with minimal support. Because I am able and intelligent I am seen as a capable of doing this. But I'm not. And I don't want to.

All I want is a 'safe corner' - somewhere to live where there are people to help me when I need it and make sure things do not get out of control when I am unable to get it together to ask for help in conventional ways.

With this support in place I do a lot: 10 hours a week voluntary work for Oxfam and mental health service user representative work (which means attending scary meetings with people whose names and faces I can't remember from one meeting to the next, and who mostly don't realise this!) The more I do with the support there, the more able I come across. Take away my support and then what?

Right now the future really scares me.

Ametrine Ruth Lavender

What it's like to be me by Sue

I suffer from something that prevents me from being the person I would like to be. Simply explained, I am like a bird in a cage that has wings but cannot fly. I appear to have all the outward attributes to qualify for 'normal' but it is what is going on inside of me, the unseen, that makes me different.

I want to join in with others and I try, I really do, but despite my best efforts, I just can't seem to get it right.

The door to my cage is open and I converse with others in a limited fashion, via my open door, but although my wing flaps up and down, my feet stay firmly stuck to my perch.

I have only just become aware that this condition has a name and that there are other adults like me who have somehow muddled through their twenties and thirties and by, the time they have reached their forties, they are burnt out with the sheer effort of trying to fit into a world that is far too abrasive for their delicate sensory systems.

We are locked inside our own world, as if surrounded by invisible, clear glass. We try to reach out, we try to connect. Our hands are extended in friendship and our hearts are warm but somehow, despite our best efforts, we just can't seem to connect with others.

Perhaps if I try harder, maybe it will happen. Perhaps if I push myself, maybe it will happen. Perhaps it is shyness and just needs to be overcome. Perhaps I should seek out someone like me, and then perhaps we can be friends. Perhaps, perhaps, perhaps....

I avoid people who are too loud, too abrasive, too intrusive, too pushy and too opinionated as they seem to mar my very senses and bruise me with their forceful brashness. I find temporary withdrawal is the only solution for me; sometimes it takes a few hours for me to recover sometimes a few days.

I find offices noisy and overwhelming and look for jobs where there will be fewer people and less noise and chatter. I know there are jobs that I would be good at but cannot cope with the social interaction that is required within an office environment.

Excesses of any kind are jarring to my senses. Too hot, too cold, too draughty, and too noisy. I cannot tolerate dark rooms as my mood darkens in sympathy. I need to sit near window that lets in natural light or be in a room that is well-lit. I prefer isolation and working alone to enforced, prolonged interaction with others.

Conversation flows so freely and naturally for others, but for me social interaction takes immense effort. Content is contrived and invented rather than spontaneous and free-flowing. It can be very tiring and after a while, conversation dries up and there is an immense, overwhelming need to walk away without having to explain why.

I do enjoy one-on-one interaction and find this much easier to deal with, but unless the person is aware of my limitations, then even this can become difficult to maintain for any length of time. My maximum interaction with another, even with someone I am at ease with, is usually about two hours. After that I need to 'withdraw' for a period alone, so that I can top up my batteries – they run down so quickly!

However, in complete contrast to this, I can also fall into one-sided conversation where it is me doing all the talking. This is another oddity of the Asperger sufferer. When we do have something to say, we tend to be like every mother's nightmare child who interrupts the whole time. Once we get going, we find it hard to hit the 'off' button ...

The plus side to Asperger syndrome is that sufferers are usually methodical in their work and get great satisfaction from doing a job well. They have a keen sense of right and wrong and are generally good time keepers. They are happiest just being allowed to get on with the job, rather than having lots of interruptions or conversations going on around them. They are also very intuitive.

My job is an audio-typist working for an orthopedic surgeon, typing medical reports. I am in an office with just two others, one part-time and one full-time, and we each have our own office, so this job is perfect for me. My office is full of natural light with big windows and high ceilings and I work 16 hours a week.

I believe that Asperger sufferers and non-Asperger sufferers can co-exist together and if co-workers, friends and family are informed about the condition and are aware of how it affects people, then there is no reason why an Asperger sufferer should not be able to lead a reasonably happy and fulfilled life, albeit on a slightly lesser level that their 'normal' non Asperger counterparts.

My life with AS/high functioning autism by Nick Marshall

I need a quiet and orderly life, I do not like change and I need to go at my own pace if I am to perform well. If I lose my pace I become over stimulated and end up doing or saying silly things because I lose my ability to concentrate and focus. This over stimulation was largely responsible for the tremendous obsessions I used to get, which would take over my life and agitate me so much. My obsessions were a desire to try and make some order out of the chaos around me, which I found hard to bear. I'm much better now at stepping back and finding my own pace. But I still pretty much like things to stay the same, to stick to what I know. When I'm faced with the unfamiliar, things fall apart. Just the other evening I was getting my dinner all I had to do was follow the instructions on the base of the package – something I've done many times before – but this time the instructions were slightly different and demanded more of me than usual. That did it. I couldn't cope with this change. I found it so unsettling that I decided to go without dinner rather than continue.

Like many others with AS, I have as much difficulty organizing my thoughts as I do organizing the activity I'm doing and this affects everything. Organising daily life like buying clothes, changing clothes and cleaning is difficult as I lack a clear strategy. I need structure and clear rules but I am unable to implement them myself. If I go too fast I feel anxious and cannot concentrate because I become frustrated and angry and I get nervous/obsessive tics. Angry because of the many normal demands placed upon me. I have difficulty in processing so much information all at once. I have difficulty putting things in order in my head and this is usually the case when I write or when I speak, it's that semantic pragmatic thing.

I have problems with social communication such as facing people I don't know. I fear the conversation. I fear I may not be able to speak well or, even worse, be unable to speak at all. I cannot organize my life well or do things that most people take for granted. I cannot go into a shop and do normal things like discuss which curtains I should buy or ask advice. This is further impacted by my reluctance to put myself in such situations – it's so much easier to avoid them altogether. I can't seem to take the initiative and, when I am not sure what to do, I will often do nothing at all. For instance, I am not sure how to speak to the postman at the door, so, often, I will not answer the door. This problem restricts my life considerably and I don't know how to overcome it.

When I'm listening to a person, I can find myself missing most of what they are saying. I'm so busy trying to process what they said a moment ago that I end up missing most of the conversation. Usually I end up pretending I know what they're talking about. I've trained myself to look the part – smiling, nodding at the right time and looking interested but I find this exhausting and would rather avoid conversation altogether.

People have a tendency to speak too fast - too fast for me anyway. I can't keep up. I'm very easily distracted and then I worry that I look stupid because I've lost track. In social situations I don't know what is expected of me. I don't know how to respond. I feel I need someone to show me what to say and do. It makes me feel very uncomfortable. I feel inadequate, clumsy and stupid and it's really important to me not to come across as looking stupid. From my experience most adults give out clear signals that they think I am a bit 'backward' somehow.

I like detail, order, uniformity and predictability. I cannot live with chaos or change. At school, when it came to the end of the day and we had to tidy up, I would be completely lost. I just didn't know what to do or where to start. I needed someone to tell me what to do. To make things worse, it was a time of day when the other kids would get excited and noisy. This would distress me and I'd end up just sitting back and not participating at all. I also remember sitting in the classroom and missing pretty much everything that was said. I couldn't take the initiative to put up my hand and ask for help. Again I was afraid of looking stupid when I knew I wasn't.

I cannot live in chaos. I know this sounds unrealistic but I need perfect order. If I find chaos I cannot function properly and all I want is to back away and make order in my own private world.

At the ripe old age of 58 I have just been diagnosed with Asperger syndrome. This comes on top of a fairly long-standing depressive illness. Being very, very single – and unemployed – I am horribly lonely. Is there someone who would become a pen-pal of mine?

By profession I used to be a nurse until ill-health forced me into a premature retirement. Since leaving nursing, I have done voluntary jobs such as working in a night shelter and a drop in centre for the homeless. Time now weighs very heavily on my hands and I would love to have someone with whom I might correspond. My main interests are current affairs/animal rights, classical music and spirituality/theology. If there is anyone out there (particularly female), I would love to hear from you. Thank you in anticipation - **Simon**

Continuing our serialisation of the speeches given at the Asperger conference Institute of Psychiatry, 10.09.2004

Don't sweep sex under the carpet - Lynne Moxon

Many young people with Asperger syndrome (AS) want relationships, though a few do not, but it is the lack of social understanding, which forms part of the diagnostic criteria for AS, which can make it difficult to form relationships.

The inability to look at things from another person's perspective can make relationships difficult to sustain. In some circumstances a person's sensory sensitivity can lead to problems with the intimate side of sex.

Older outcome studies looking at the prognosis for adults with autism (Rutter 1970; Kanner et al.1972) showed no marriages and few dating. There is still little research about the frequency of marriages and long-term relationships but more recent outcome studies of high-functioning adults (Larsen and Mouridsen 1997) found some marriages and long-term relationships. Hellemans and Deboutte (2002) recently found a high percentage of relationships in high functioning autism, perhaps reflecting the wider diagnosis now made.

Clinical experience, books by persons with AS (Slater-Walker 2002) and their partners, and increasing research now show many examples of long-term, successful relationships.

Henault and Attwood's research (2002) found that people with AS and high functioning autism have levels of sexual desire and imagery comparable to those of the general population. However the AS sexual profile differed in several respects from that of the general population. Body image, sense of belonging to one's sex and the erotic imagery of individuals with AS seem to be less influenced by social norms.

Adults with Asperger syndrome would appear to act according to their internal desires regardless of whether they are directed to a person of the same or the opposite sex.

Although Henault and Attwood (2002) found that the majority of people with ASD are interested in sex and show a wide range of sexual behaviours, they also found that individuals with AS and high functioning autism have poor levels of knowledge regarding sexuality.

Adolescents with AS have less social experience than their peers and are less tuned to social rules. They see no problem in being attracted to people of the same gender, (Henault 2003) and may express a wish to change sex if they feel they would be more comfortable as a female, for example. However, gay groups have social rules too and the person with AS who takes on an overly camp persona, imitated from TV, may find he is rejected by mainstream gay groups.

Some young people confuse the comfort and enjoyment of friendship with sexual attraction.

'Difficulties in interpersonal functioning can arise when someone is not aware of his or her feelings, has trouble expressing emotions, expresses them inappropriately, or misinterprets the feelings of his partner.' (http://www.bbc.co.uk/relationships/)

This site is for the general public to improve their relationship skills but the description could be specific to AS social functioning and the difficulty in recognising emotions in oneself and others. This will happen at times in any relationship but more often in AS.

Many young people have a wide vocabulary of sexual words but may not know what they mean and will need guidance if they are not to be teased or bullied in school or work.

Young people with AS need to learn the rules: that there is more than one way of saying 'no' and to understand that there are subtle non-verbal signals of encouragement.

Verbal interactions can be complicated; the phrase 'would you like to come up for coffee' needs knowledge of context to be interpreted correctly. Standard school sex education is not sophisticated enough to help an adolescent with AS.

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Unfortunately, due to space restriction, we were unable to publish the whole of this article.

Copies of the complete, unedited version are available from *Asperger United* - 020 7903 3541

Request for volunteers for a research study: linking, and telling the difference between, thoughts, feelings and behaviours

You are invited to take part in a research study. I am looking for people who live in East Anglia – particularly, Cambridgeshire and Norfolk (King's Lynn and Norwich areas). I am a trainee clinical psychologist studying for a doctorate in clinical psychology. I am undertaking this project to investigate whether adults with Asperger syndrome (AS) or an autistic spectrum disorder differ from other adults in the ability to link and tell the difference between, thoughts, feelings and behaviours.

Involvement in the research would require just one meeting with me, which would last approximately 45 minutes to one hour. During this meeting I will ask you to do some practical and verbal tasks. Detailed instructions will be provided and I will explain the tasks in more detail before you start.

You are eligible to take part in the study if you:

a) have AS or autism
b) are 18 years of age or over
c) attended mainstream school (i.e. not a special school)
d) are able to read
e) do not have a neurological disability (injury or illness that has affected the brain) in addition to AS / autism
f) have never taken part in cognitive behaviour therapy.

If you would like to help out, or if you have any questions, please contact me by email (H.R.Johnson@uea.ac.uk) or telephone (07734 669876). I will provide an information sheet with more details about the study and provide a consent form for you to sign if you would like to take part. The study has been granted ethical approval by the University of East Anglia Schools of Health Ethics Committee.

I would like to take this opportunity to thank you for your time and help.

Helen Johnson
Trainee Clinical Psychologist
(Supervised by Prof. Shirley Reynolds and Dr Suzanne Collins)

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Volunteers with autism or AS needed!

We are researchers at the Institute of Cognitive Neuroscience (University College London) working with Prof. Uta Frith. We investigate how people with autism spectrum disorders process information. We are looking for people aged 18-65 with a diagnosis of autism or Asperger's syndrome who would like to participate in our study. This would involve you coming to us at the Institute of Cognitive Neuroscience, 17 Queen Square, London (2 minutes' walk from Russell Square tube station).

The testing involves pencil and paper, problem-solving, and computerised tasks. These will take place over a half-day or full day, depending on the amount of time you have available. You will receive a payment for your time and your travel expenses will be reimbursed.We are also planning to do brain scanning studies in the future: let us know if you would like to participate in these.

To find out more about the study, please contact: **Caroline Catmur c.catmur@ucl.ac.uk** or **Geoff Bird g.bird@ucl.ac.uk** or phone us on **020 7679 1138** or write to us at the address above. For general information about our research group see **www.icn.ucl.ac.uk/dev_group**

Caroline, Geoff and Uta

Would you like to help with research into AS?

We are a team of researchers from the Institute of Child Health (part of University College London) and Great Ormond Street hospital. We would like to contact adults from the UK (aged between 18 and 65) with a diagnosis of autism or AS to take part in our research. We are investigating how emotion affects memory and perception in peoplewith these diagnoses. The research would take about three hours, for which we can pay you £30. We would want to visit you for two hours on one day and then for one hour a few days later (whenever would be convenient for you). We would be happy to visit you at your home, or any where else where you would feel comfortable. Alternatively, you could come to us at the Institute of Child Health in London (we would reimburse your travel expenses).

If you are interested in taking part please email Ben Corden on b.corden@ich.ucl.ac.uk or call on 0207 905 2168 and we will send you an information sheet.