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Workshop for Partners of People with Asperger's Syndrome

Tuesday 2nd May 2000

Queen's Road Baptist Church, Coventry

General Overview	2
Profile of Abilities	2
Typical History of Relationships	7
Qualities of the Person with Asperger's Syndrome	9
What Attracted you to your Partner?	13
Choice of Partner	18
Family Life	21
Social Life	36
Intimacy	38
Emotion Management	43
Issues	45

General Overview

Welcome to today. This is a workshop so I am hoping that at any stage if you want to make some comments or additions, please do so, because what we really want to do is to exchange our knowledge base. You have an enormous amount of information, probably on the one individual in your life who has Asperger's Syndrome. I have a lot of information on many people on the autistic spectrum and that's where I'll begin today, because most of our knowledge started on the severely autistic person, who was very conspicuous, the silent aloof child, first identified over 50 years ago, and of course for such individuals we have developed programmes and understanding for them, but their outcome has usually been someone with high support needs.

As we examined the continuum further and further, we explored what we call high functioning autism or perhaps Asperger's Syndrome, so in other words, somebody who is talking, who may be at an ordinary school, who has intellectual abilities. We are now exploring the upper end of that continuum for somebody whose intellectual abilities may be at the superior end and somebody who has effectively camouflaged their difficulties, such that only those who know them intimately know the difficulties that they face.

Now we use the terms autism and autistic spectrum and Asperger's Syndrome. In a way what we are talking about if we are dealing with your partner may be what I call the Asperger personality type. There is a debate as to whether to call it a personality disorder or a personality type. I prefer in a way to call it a personality type but it describes a certain profile in that person's character. They may not need obvious assistance in finding a job, in finding a relationship - obviously you wouldn't be here if that were so, in other words the person has a relationship, so it may be best described as a personality type that is part of that continuum.

One of the things I'm going to go through today is first of all describing a little bit of what Asperger's syndrome is and how it affects their later relationships, and then go through with you to brainstorm some of the issues you face that are common issues and in particular some of the strategies that you've used and been successful or things to avoid in a way, because I think what I'd like to have at the end of today is some suggestions of what may help or not in certain circumstances.

Profile of Abilities

Almost by definition, a person with Asperger's Syndrome has had problems with peer relationships, friendship skills, but we know that the more skilled you are in friendship skills, the better you are in teamwork skills as an adult and relationship skills with your partner. The more friendship skills you have, the more you've understood about people perspectives, how to get on, how to manage conflict. The more you relate to people the better you are able to cope with various issues and eventually leading to your final partner, when that friend becomes a partner. Also the person with Asperger's Syndrome, from work I'm doing, suggests that they are poor in what I call characterisation skills. They tend to be very black

and white about who they like and who they don't like, and who they like they may adore and think is wonderful and those they don't like are treated with great disregard for that person, but they can be very poor at character judgements in working out who is potentially a good friend, reading between the lines etc., so often they have difficulty in what I call characterisations and work I am doing with the kids is trying to teach them characterisation skills.

A difficulty understanding the codes of social conduct, that is the unwritten rules that other people just know when they're broken and how to repair them. Most of our codes of social conduct are designed not to offend the feelings of others. If the person with Asperger's Syndrome is mind-blind or mind-myopic, in other words they can't focus or see those things, then often they're not aware that they've hurt people's feelings or broken the codes of conduct, or identified the cues that in this situation this is what you do. So here, they are often breaking the codes of conduct, not maliciously, not in a psychopathic curiosity sense; they are just oblivious to some of these rules.

There can be problems of empathy, that is reading and responding to the cues of the emotional state of other people. One of the major things that we do with autism and Asperger's syndrome is look at eye contact. There are four reasons why we use eye contact, one is to read the feelings of the other person, and when I explain this to the kids, it's like traffic lights, green or red, so as you look at a person's face you identify the nod, the smile, green light keep going; but if you read the head going up, the embarrassed look, the agitated look, the bored look, you stop, repair, change what you're doing, and often the person with Asperger's Syndrome is not reading that person's face, tone of voice, body language or social cues, to take on board to modify what they're doing. It's like a one-track mind, once they're on that track that's it, it doesn't matter what feedback you give, even if it's perceived, it may not change what they're going to say or do.

Difficulty with the art of conversation, that is the pragmatic aspects of language, the conversation skills, the prosody, and being very pedantic. Quite often you say "Please get to the point", summarise it, and there's all the extravagant detail, this is in relation to what we call weak central coherence. In autism and Asperger's Syndrome detail is important and so what the person is doing is giving you extraordinary detail without getting to the point, the gist of what is going on, and so quite often you get this very lengthy monologue of whatever the person is interested in without reading the signals that you're bored or summarising it, but very, very pedantic and any mistake that you make in your grammar must be pointed out. The person is not being rude, they're just noticing the mistake and they think they're doing you a favour by pointing out your mistake.

There is often a history of special interests which when they are in the courtship phase may be very endearing, with his interest in trains, or rocks, or whatever it is, how wonderful and boyish until you realise that they're more in love with the interests perhaps than people, and so their special interest is something that may dominate their thoughts or conversation. It may be their way of obtaining friends and relationships, as I'll go through later on, seeking people with those interests, and I do say that Star Trek conventions are reunions for people

with Asperger's, and trainspotters as a British institution is a wonderful opportunity for such reunions. So there is often a history of special interests, of a strong preference for routine and consistency, and that is the person likes everything to work like clockwork and everything to be done at a particular time - so tea is at 6 o'clock every evening, we must do this on a Tuesday, etc., and if they don't have that occurring, it's not frustration it's a panic attack, it's basically anxiety that the person has to have that routine, so flexibility, spontaneity, may not be their greatest attribute.

Some have problems with movement skills; there can be difficulties with co-ordination etc. There is a suggestion now that there are quite distinct problems with movement and self-care skills, and so quite often the person may need assistance in some aspects that require manual dexterity. Cognitive skills, tending to be what we call verbalisers or visualisers. Some of the verbalisers are very good with language and may have a career in law for example or as an author in a number of ways, but there is a fascination with words. Others may be visualisers and may be phenomenal in their ability with engineering, accountancy, numerical skills, etc.

Some have problems with executive function. This is a new area we're looking at. It's a bit like a chief executive of a big company who plans, organises, and sees the big picture, is getting information from all sources before being impulsive - it's like being as a good chief executive should be - and as my dear mother would say "They couldn't organise a piss-up in a brewery" and so somebody has to be their executive secretary, if that's not how they first met as being their secretary, in terms of organising their schedule, coping with things, having a rough draft etc., so executive function may be that they require assistance in some aspects of daily living, which is in stark contrast to their intellectual ability or prowess in their chosen career.

Some have problems with sensory perception, there are certain noises which may be infuriating, certain light intensity, textures of clothing, and some of the interesting things can be a hyper-sensitivity to some sensory stimuli but a lack of sensitivity to others. They tolerate pain at a level that others wouldn't consider and become quite stoic in tolerating pain. They may accept cold and cold water in swimming for example, to the level others wouldn't identify. I am also finding in the work I'm doing in what we call cognitive behaviour therapy, which is a way of helping the person cope with their emotions, is that they may not be perceiving low levels of emotional cues that you would pick up with heart rate, perspiration, or you would start to pick up the cues of those early warning signs of emotion, they may not pick them up until they are really quite extreme. So sensory perception can be acute in some areas and relatively numb in other areas.

Do you think.....?

That's an interesting question, the question is do they pick it up, or do they know what it means. I think that's something that needs to be investigated. Certainly when I'm working with the kids and picking up the signals, they don't seem to recognise the significance of them, and that's something they're having to be actually specifically taught, that is the signals

within themselves, as much as we try and teach them to read the face and those sorts of things, they don't seem to be picking up the signals, and certainly other people have the impression that they're not broadcasting those signals until it reaches a threshold where it comes out as quite severe.

So one of the features of Asperger's syndrome is probably introspection - of thinking about themselves and all those sorts of things and vocabulary and so on, so it's hard to know literally what's going through their minds at that time, because we have a fluent vocabulary to describe that and often the person with Asperger's Syndrome is very uncomfortable about self-reflection in that area. Talk about trains or anything like that fine, anything practical, observable, and they'll talk for hours, but when it becomes abstract and personal, they're very clumsy in that area, so really I don't know. First of all you've got to pick up the signals, secondly you've got to know what they are, and thirdly you've got to know how to respond to them, so there could be a breakdown at any one of those points, as I'll come to later on in emotions, it's like comprehension and expression, some with Asperger's syndrome will understand what emotions you're portraying but don't know how to respond, but I'll come to that later. Do ask questions.

Can I just ask, hypochondria, does that feature?

I think there can be a confusion in the perception of sensory experience. The hypochondria sometimes can be an expression of an anxiety disorder, so what may happen is that for some with Asperger's syndrome there is almost a constitutional predisposition for anxiety, but what they're doing is looking cognitively for a justification for those feelings. For young kids, it may be thunderstorms, for older people it may be hypochondriasis or things like that that gives a justification for those feelings that they're going through, so sometimes when you work on that and shall we say alleviate the focus of that anxiety, it will then flow to something else, so you have to really work with the anxiety rather than necessarily just the focus of that.

We've got to deal with three emotions here, anger, anxiety and depression, because as a group I'm afraid they are prone to those three. The anxiety, we have a number of medications that can be prescribed to reduce the anxiety but it won't help you deal directly with the cause of that anxiety or ability to understand it themselves and cope psychologically. So anxiety is an issue. Anger is an issue which I want to go through in more detail because quite a few with Asperger's syndrome are notorious for their short temper and ability to become quite explosive, there's also the issue of depression as well.

The situation with me is when I'm trying to explain how I feel about an issue, then I see the anxiety coming out, so while I'm having to deal with what's happening to me, I have to deal with that as well.

Yes, that anxiety may be uncertainty of what's going on, because it's not black and white, it's coming up as a confusing area so that the person is being overloaded with information that they're uncomfortable with.

And it's generally the point that perhaps I am losing control or am getting stressed with the situation - the anxiety becomes the main focus of the crisis then.

I'll give you an illustration I use of being confused in a way, this was when I was seeing a family, I don't know whether I mentioned this at the last workshop, but a 7 year old child with a diagnosis of Asperger's syndrome was under discussion, it was quite clear that the child had Asperger's Syndrome but the child went next door, so I talked to the parents over the kitchen table about the diagnosis and the mother knew, classic in the sense that she was a very motherly mother, very demonstrative, emotionally needy person, for me that's quite obvious, and I went through the diagnosis and she burst into tears, not bad tears, but a sense of partial relief, yes I know what it is, but the tears were there, and she was sitting next to her husband, who was absolutely still, frozen. He didn't show the affection and support she desperately needed. He then went next door and as he left his wife said "Do you think my husband has Asperger's syndrome?" and I chatted to her and said "yes I think he does" and she said "Do I tell him?" so I said "only if he asks".

That night he did ask and I saw him the next day to go through that, and I went back through that incident of when his wife was in tears and to me needed a cuddle, and I asked him about that and he said "Yes I knew, but I didn't want to do the wrong thing". So in other words he would rather do nothing than risk the wrong thing, so it wasn't an absence of appreciation of the cues, he was "frozen" because he didn't want to make the mistake of doing the wrong thing, because in the past he may have tried to do something and got told off, that's the wrong thing to do, and that's what a lot of those with autism and Asperger's syndrome will often do, they'd rather do nothing than risk doing the wrong thing, so he picked up the cues, he knew she was upset, but he didn't want to make it worse by not being sure of how to respond. You almost have to imagine programming a robot and say I need a cuddle. I am anxious because etc and unless you are blatant and up-front, you can't use subtle cues, subtlety's not in it I'm afraid, you just have to say this is how I feel, this is why I feel it, this is what you need to do, and often there's a great sense of relief, "Oh I've been told what to do" rather than "I'm expected to know what to do", so sometimes you just have to say, this is what I need at the moment and you're going to do it.

The trouble is I think that's one of the hardest things that I find to do. I go along with them being frightened because I would try and talk to C and there'd be total silence and then when we had the diagnosis we found out it was because he was frightened of saying the wrong thing - but I'm sorry, if I'm really upset because he's upset me, I don't want to say "give me a cuddle", and that is where I think some outside help is needed. I mean I don't want to say "I want a cuddle", I want somebody else to say to C "In this situation if you give her a cuddle, you've got your brownie points".

Yes, I think this is where, and later on we'll talk about it, the relationship counselling does need to come from an independent person and they may accept it from an independent person more readily. So it's basically as much as we tutor the kids in how to have a friend, we need to tutor the adults in how to have a relationship and we're doing a lot of work now on teaching friendship skills for kids, which is great and they're getting friends. But the other

point is one of the friends is potentially going to be a partner, and they've still not come to the end of their problems, it's a new chapter in the social relationship problems that they have, but this is a completely different ball game literally, from playing soccer with the kids in the playground to a relationship with a partner. Anyway, I'll move on.

Typical History of Relationships

So we were talking about sensory perception there. Now in the typical history of relationships there has often been problems with friendships and immaturity, according to their IQ, in what makes a good friend, so they played as a kid with much younger kids who they can often boss or at that level of maturity, or older kids who mothered them or changed what they're doing, so often they're very immature in their concept of friendship and a lack of experiences of friendship over time and social intuition of knowing what to do with friendships.

Unfortunately this leads to a vulnerability of social, sexual and physical exploitation, for some unfortunately they are born victims, and I say people with Asperger's syndrome promote in others the maternal or predatory instinct. Usually their partner is very maternal but they have met people who are very predatory. It may be bullying and teasing at school, it may be sexual exploitation. Quite a few of the ladies with Asperger's Syndrome have had incidences of date rape. Some of the young men with Asperger's Syndrome, of homosexual rape, so often they've not picked up a mutual breakdown in signals, so sometimes their experiences of friendships may not have been good ones.

One of the things we do notice is that the special interests have a progression. When they are very young it tends to be sensory experience, then its collecting particular objects that other kids are interested in, then it's a concept like trains, trucks and transport, then it can be a person, and here the person develops an infatuation with an individual. It may involve stalking that individual, phenomenal knowledge of that individual, and I'll go through this in more detail later on, and the special interest is now a person, especially in teenage and early adult years, which may be very flattering for the person to have that degree of interest, but there's an obsessive nature to it. So here, there can be an infatuation with individuals that if it's not returned the person can get quite angry with them, and actually can get into trouble with the police.

It's also a difficulty in managing emotions, particularly frustration, conflict resolution and mood swings. It seems as though, the way I describe it is that if we call ourselves neuro-typical, we are born with a very good emotional toolbox with a manual of how to cope with our emotions, a built in intuitive manual, and so these guys have only one tool in their toolbox to manage emotions, their special interest, so then if it goes wrong, off they go to the special interest as a form of retreat, relaxation, etc. Whereas what we do is we have a system whereby other people are the cause of our social emotional distress, but also the solution to our social emotional distress, but that doesn't occur with Asperger's syndrome, so if we have emotional problems we talk to somebody about it, we share our experiences, we

validate what we're doing, we get a second opinion, we get advice on what to do, that person cheers us up, so we use other people as a mechanism of repairing our emotions.

The person with Asperger's syndrome uses themselves, and they go off-line for two or three days to work out what it is but they don't let people in to solve their practical problems or their emotional problems. You watch the kids at school when they've got difficulties, they don't ask other kids to do things, they tend to be one man shows in many ways but that also goes for emotion management, and in a relationship you're expecting the person to open up about their feelings, so as their partner you can assist them in some of their emotional difficulties, but that may not be something the person with Asperger's syndrome finds easy to do. A lot of our work in emotion management is giving them tools in their toolbox to first of all recognise the signs, and a menu or variety of options to manage their feelings.

Also we have problems with the source of information on relationships, because if the person hasn't had lots of friendships, what are they doing with their time, watching television, or their special interest. What do they watch on television, soaps, and soaps become a source of information on relationships, with the dialogue from soaps and with the development of extreme interest in inappropriate videos etc in relationships, so often the person may not have had the best source of information.

They may be a late developer in social emotional maturity and for some partners, their partner may have the emotional maturity of a four year old and I'll come to that a bit later on, because that means that there is sibling rivalry with their children, and there is a degree of behaviour that's like a four year old - tantrums in relationships. So if I'm talking to a mother who has say two children, one with Asperger's syndrome, and a husband who I suspect with Asperger's syndrome and she says I've got two children, I say well actually you've got three children in some areas, and you have to be a mother in certain aspects which is not what you expected to be with your partner. You expected it to be a partnership and that can cause quite a few problems because you are now the mother figure, the father figure etc, it's being a solo parent almost.

But in choosing their friends, the person with Asperger's Syndrome, remember I talked about not having the usual codes of conduct which determine who our friends are, in Asperger's syndrome that means that in their friends they're not sexist, quite a few of the kids, I can go through a lot of the reasons why, but many of their friends when they're children are girls not boys, because boys bully and tease them, they play ball games, they're not good at it, so they play with girls.

Some have major problems when they're younger of wearing girls clothing and being a girl and I find later on, some have a feminine voice and body language, which is because most of their life has been spent with females and it's accommodating to that female intonation pattern and movements, but when they're teenagers it is misinterpreted by others as being gay, which causes all sorts of difficulties. They're also not ageists; they may not choose somebody in the same age range.

Now I'm going to introduce Dr Venetia Young. Venetia is a friend of ours for twenty years, because my wife Sarah's father is a GP in the Lake District, and yourself and Gavin moved in to the practice in the Lake District, and we had kids at the same time and we've known each other for a few years. Do you want to explain your involvement in Asperger's syndrome, why you're interested?

Why I'm interested, well my eldest son has Asperger's syndrome and semantic pragmatic language disorder, and I read Tony's book two years ago. I trained as a GP and then I did a family therapy training ten years ago. I'm now working in an adult mental health setting, yesterday I reviewed my caseload and 14 out of the 34 families have got Asperger's syndrome as part of the diagnosis. I think it is extremely prevalent in the adult mental health population.

I'm working with four couples at the moment and one couple, the wife I came to your talk two years ago, and it's been a journey of discovery. I finished working with them last Wednesday and their message to the group was that there can be a lot of positive things that can happen with finding the right counsellor, and I think that's much the same with the others. This couple say they are truly happy now, and there was a lot of violence in the relationship. But it certainly gave me a lot of hope there.

I think with that couple one of the major features, as we'll go through later on, is motivation - the partner with Asperger's Syndrome wanted to make the relationship work, and what I find fascinating with Asperger's syndrome is that once they apply their intelligence to a problem they are brilliant at pursuing it. The issue is motivation and if they're motivated, they learn, they do it, they're great, and it will be a successful relationship, but the biggest problem is motivation - it's understanding why you do that. If there is a motivation there, then they will learn the skills and be successful.

We can't make value judgements of what type of relationship will work or not work, but quite clearly the person doesn't usually fit with the conventional of the male being two years older than the female, both coming from the same intellectual, cultural, religious background etc. They will choose who their partner is, but it may be on different criteria than the usual cultural expectations. Asperger's syndrome I describe as coming from a different culture and in that culture, there may be different criteria in choosing your partner.

Qualities of the person with Asperger's Syndrome

There are qualities in the person with Asperger's syndrome, you wouldn't have married or be having a relationship with them unless they have qualities in some ways, so one of the aspects are their ability in their career or special interest, with that one-track mind determination, inflexibility, etc., they can be very successful in their chosen career, which may be in industry, it may be in academia (I always use that phrase "universities are sheltered workshops for the socially challenged") and as such here the person is appointed academically for their intellect not their social skills. But when you go for a job you have got to show your ability to sell your personality at the interview and work effectively as a

team member, and one of the things we hear today about is relationships, another whole ball game is learning teamwork skills as an adult in your job.

Attention to detail. They will spot mistakes. If ever you want a contract lawyer, get somebody with Asperger's syndrome, because they will spot aspects of that where I will go "Yes, I've got the gist of it", no, they watch every comma, every bit, so in the work force, the person may be renowned for their attention to detail. You give it to this person and they will very thoroughly check it out, they will proof read texts and spot any grammatical errors etc. Certainly, when I wrote the book on Asperger's syndrome, the biggest mistakes were picked up by those with Asperger's syndrome and I learned not to be offended by it but just to accept that those are genuine errors. They speak their mind to a fault.

It's like kids under the age of four, because over the age of four ordinary kids will learn by the social context, I've got to change my language or think it not say it, and here they are what I call self-appointed revealers of the truth. It doesn't matter if it's the school principal, the managing director or whoever it is, they will say without fear or thought of the consequences both to themselves and to the other person. One of the things we use in the assessment is on the concept of lying, and I'll come to that later.

But the concept of a white lie - not to hurt people's feelings, why - when you talk about that, they're totally bewildered, why not say the truth, what they find so infuriating is other neuro-typicals don't tell the truth - they lie, they change their minds, they're inconsistent, and they want everybody to be like themselves and up-front and honest. They have a determination to seek knowledge and the truth and will pursue a particular interest when others would have given up, would have realised and changed to something else, but they just go on and on and on, and sometimes come up with a successful outcome.

This business about speaking your mind, I have problems getting my husband to do exactly that - I have to probe to get what he really thinks about something.

That may be the difference between honesty in facts, that somebody has made a mistake, and a difficulty in formulating how to describe their inner feelings or what's going on in their mind on certain topics. *Maybe, yes.* So here the person may be unable to formulate in words that you can understand, what's going through their mind.

Also I think it's that he hasn't particularly thought about that, it's never crossed his mind to have an opinion on it, and then when I ask I say "Well what do you think" and he says "Oh" and there's just nothing, a blankness.

There are two issues there, one is thinking about thoughts may not be something they do - the other is that often their weakest way of learning and communicating and understanding is verbally, and so we find sometimes they have a difficulty in putting thoughts into words. Interestingly when I'm working with couples who for example one's a musician, the person with Asperger's syndrome is a musician, they can convey their thoughts and emotions in music perfectly, and they can create music that goes with that.

I spent a few hours talking to a lady whose son has Asperger's syndrome. She is a journalist with a phenomenal knowledge on rock musicians who has actually edited an encyclopaedia of rock music, and we had great fun going through the profiles of various rock musicians who probably have Asperger syndrome, both as musicians and composers, and what seems to be occurring is that the person may be able to have a greater eloquence in a way through visual means in art or music, or sometimes even poetry. Certainly sometimes in written prose, but not in conversation. To talk about it is their weakest point, so when you're doing counselling, where our main vehicle is talking, and for the person with Asperger's syndrome that's their weakest way of understanding and expressing themselves, that's why when I'm working, I do a lot of drawing, any other medium, that I can get through to the person, because I may get more understanding through visual, musical, those sorts of techniques, or I ask the person to write me a letter, or an email, and then go away and they formulate their thoughts by fax, email or a diary entry, more than they can in conversation.

My husband has actually written over 100 poems saying how he feels and I didn't read them, and I've read them since.

They can be so illuminating because in those few written words you can encounter "now that's what you're trying to say". *I've brought some with me.* When we have a break I'd like to have a look at those. It's just that I do know some, particularly ladies with Asperger's syndrome, who in their difficulty in understanding relationships with others and their imagination have become authors, with their ability to observe individuals at an incredible level and the dialogue, and some of them become famous actresses, but also they can become famous authors too, and they can have an ability and insight into people and relationships that is extraordinary when you look at their own personal relationships which are very different.

Conversation free of a hidden meaning or agenda - they say exactly what they mean. Advanced vocabulary and general knowledge. Trivial Pursuit - it's amazing what the person will have remembered. A unique perspective in problem solving - it's what I call a different way of thinking, which if applied to certain situations with high intelligence can lead to major advances in science and art.

An exceptional memory for detail. One lady was amazed at her husband who I think now has Asperger's syndrome, how he would remember every meal that they had ever had at a restaurant, which sounds so remarkably romantic, but it wasn't because the circumstances were so significant, it was a phenomenal memory for every meal they had had. So this is how you can misinterpret the comments from the person with Asperger's syndrome, because when you are in love you are not logical, you don't see the signs. *Did he remember the food or the romantic conversation?* Not the romantic conversation, it was the food, we had this, and you had that, etc. Then initially oh how delightful to have somebody who is so interested in what we have done, without realising that it's the food and memory not the romance of the situation, but again when you're in love yourself, you don't see those things. *It's the wine - phenomenal memory for wine.* In fact one of the career options I've known for some has been with wines, because often with their sensory sensitivity to aromas - have

picked up aromas that others wouldn't have picked up and have an eloquence to describe the wine, but not relationships with people.

My husband worked as a bar tender and wine waiter and say at Christmas, he could go to a table with twelve people around it, and they'd all order a different drink, he wouldn't write it down, and he'd go and get all twelve drinks without forgetting one of them, and know who it was that had ordered it, and I thought he had a phenomenal memory. When I'd be talking to him and he wasn't looking at me, I'd say you're not listening to me, and he would repeat word-for-word what I'd just said and I'd think "Oh he must be listening", but he wasn't understanding the meaning or taking on board the implications.

There's another thing there, also he would be listening to the words, focusing on the words, and sometimes socialising gets in the way of that intellectual process, some with Asperger's syndrome will say and some with autism they can listen but not look, look but not listen, and teachers find this, they think the kids are off line, being distracted or whatever, and then will play back everything that they've said, it's almost as though the social side confuses their thinking process, so they jettison that to focus on what you're saying. You're thinking it's disrespectful or distracted but in fact they're taking everything in, but what they should be doing is looking at you as some form of reading your emotional reaction and picking up the other cues too, so often when we're looking at conversation, what they're doing is they are focusing on the facts not the emotional side of it, so the person can recall what you say. I find for those with Asperger's syndrome who become actors and actresses is that part of their acting is to have registered the voice of all those people that they've known in the past and they become that person - so they have the vocal intonation, everything - in fact when I'm working with social skills with the kids sometimes, one of the programmes I'll use is to take on the persona of somebody successful that they know in that area, and so they will have this store, not just of wines, but they'll have a store of fragments of conversation which they will replay as a form of social echolalia later on when they're acting.

Going back to conversation free of hidden meaning or agenda, I think one of the things you said that quite often partners are sort of very maternal or very feeling. I'm starting to think I'm perhaps quite literally too sensitive to how he might feel, and I tried to tell him I wasn't very happy about things and you mentioned echolalia, he'll finish the sentence and repeat part of it, which I think is a distraction, and when you're trying to discuss something emotional it's difficult to be totally consistent, because you're thinking about how they might feel, so you're going around the houses, and he's chewing it over in his mind, then he started correcting the grammar. I did say forget the semantics, and in the end I was brutally honest, and it's horrible because it goes against everything you're brought up to feel, but brutality in many ways is easier for them, because then they can start to think how to respond and that's something quite hard for us to get over really.

You've got the gist of it, you can say it in many different ways, but when you say it again, it's not exactly the words you used before, so it's perceived as different, so there's confusion going on, you know it means exactly the same but for the person with Asperger's syndrome, it's slightly different words, slightly different, yes

Some can have a very strong sense of social justice. The usual expectation of a person with Asperger's syndrome is to go into a career of academics, engineering, those sorts of areas, but there's a certain proportion who have a very strong sense of social justice and will have a strong feeling for the underdog, they may become a nurse, veterinary surgeon, somebody who deals with the down and out people, and may have a compassion, and some become teachers, especially of early primary school and infants school. So some do have a strong sense of social justice, some go on to the police force in a number of areas, but they can want to right wrong, some will go into politics, usually extreme right or left wing politics unfortunately.

My son got into a lot of trouble at school in those situations because he stood up for underdogs beyond the point where it was in his best interests, and he was the one who ended up getting the flack to the point where he got excluded from school on one occasion.

In a way I view Asperger's syndrome as fitting into the active or the passive group as children, which is a gross simplification, but active or passive. The active group are more active but odd, abrasive, potentially aggressive, conspicuous and more likely to be flagged as having a problem and more arrogant in a way, whereas another group, which are ones that aren't picked up because a lot of girls have this, are the passive group, where they're more tolerant, they are more likely to suffer in silence, they can be more compassionate, they can be camouflaged by other people who recognise that they have problems but they're nice kids in a way and they mother them or cotton wool them all the way through and those passive ones are often not referred to diagnostic clinics. So some clinics are receiving a disproportionate number of people with Asperger's syndrome with anger management problems, psychiatric disorders, etc; they exist but when you look at the actual epidemiology that's going on, they're seeing one side of the distribution which tends to be those who are the active. The passive ones may never be picked up or perhaps not until later on when they have a child with Asperger's syndrome. They're just odd, but they're getting by, and the ones who are going to be referred are those who are abrasive, who have anger management problems or depression, all those sorts of things.

Also they can be very practical in issues of mortality and grief, and quite often I notice that when a relative dies, the grief process may only be a few hours and then concern about the practicalities of things. The person's thoughts of their own mortality as they age may be very practical in a number of ways, so in a way we may suffer from our own emotionality, it allows us some pleasures, but also makes us vulnerable. For the person with Asperger's syndrome they may be less vulnerable to some of the things we are sensitive to. Also in practical issues, I have known some times when a relationship has ended - that's it, everything from that person is burned, disappears, never talked of again, it's almost as though they never existed and the person will just wipe out their total existence.

What Attracted You to Your Partner?

Now this is something I want to ask of yourselves. What attracted you to your partner originally? Do you want me to go through the suggestions or do you want to nominate

what attracted you to your partner? *He was very cheerful. Cheerful! He was always so cheerful, and it took me a while to find out that he was never serious. He could not be serious.* Right, what other things attracted you to your partners?. *I can add to that because he was always laughing, and it was one of the saddest days of my life and I was told that laughing was a defence, and if somebody rings him up and says I'm sorry to tell you that my mother's died, he breaks into loud laughter.*

I've known that at funerals where other people have been in tears, it's where you either laugh or you cry, and it's what I do when I'm working with kids with Asperger's syndrome, it's on the right dimension but it's the wrong point. The dimension is having a sadness and you have tears of joy and tears of sadness, so in other words those tears can occur for a variety of reasons. The same as love and anger can be on the same continuum.

Anyway, more on that later. What else .. I'll quickly go through the list. The silent handsome stranger, where you have, this is pure conjecture from my point of view, but I suspect that on the autistic spectrum there are actually what we call dysmorphic features, that is structural abnormalities, but not a structural abnormality of disproportionate quality like Downs Syndrome, but smallness of features, which makes the kids look angelic, and the adult look handsome, because of the smallness and symmetry of facial characteristics.

That sounds like my whole family, you've just described my husband, my kids, my grandchildren.

The silent, handsome stranger. They are good lookers, yes, and a person feels "I've got this wonderful catch". There's also an admiration of their intellect or abilities - wow that is smart. It may be compassion for their limited social skills, it may be a partner who has always looked after wounded animals or people who are in some way fragile etc., and there may be a recognition that the person is socially confused but that's where they can be helped, it's almost like he's got great intellect but I can help him socially, and belief that their character is due to their childhood circumstances, because often if you've got the family history you may have this very austere authoritarian father who abused his kids and you think well, he's like that because his father was like that and if I take him out of that home environment I will mother him and he will be all right.

I think it was his mother who didn't show affection and she has AS. He was a very gentle man, he wasn't macho, I can't stand macho men, like lager louts, and he was very gentle and very good looking.

It's the gentle man isn't it that's the attraction - now I realise. You're not going out with somebody who gives you all the history of their previous relationships.

One of the issues where we talk about multiple partners, is that the person they talk to you about, is their next partner, while they're still married to you but I'll come back to that. What they've done and I'll come to this later on is when they're starting another relationship, is talk to their current wife or next wife about that, without realising it may not be wise to

talk to your wife about the mistress you've got or whether you should buy your mistress a present for her birthday.

A friend was separated from his wife but went on holiday with us and their children and then asked her to help choose a present for the woman he was going to marry and he did exactly that. Not unreasonable! Just a simple practical problem, she would probably know what his new girlfriend would like! Going back to the gentle man, I think that one of the things is that most teenage boys are heavily into being macho, and I think that they don't pick up these stereotypes, so they're not stereotypes, so you get these men who are quite happy to like pretty things and that was one of the things that I quite liked. Yes there is that yobbo culture that the person relates to and they are often more of an intellectual level.

In my research that was one of the questions I actually asked. I found that the three adjectives that women used most were gentle, kind and quiet, as what most attracted them to their partners. When you look at gentle in the dictionary it's actually linked to almost childlike words, and once again you've got this maternal instinct that's attracted to the childlike manner. These are often the qualities that seem to attract women.

Often when I'm talking to children and adults with Asperger's syndrome on characterisation, what sort of a person is your mother, your father, your friend, yourself finally, they have great difficulty finding characterisation with which to describe themselves. Their major vocabulary is 'nice' and 'kind'. Someone in their thirties and you think haven't you got anything more precise and subtle to describe nice and kind. It's almost that that's their level of being nice and kind and quiet, yes there can be that component, gentle and kind. *They can also be non-competitive, which can be reassuring and un-threatening for a woman to be with a man who is not competing with other men. My husband just sits on the fence and stays quiet. Yes. I think you may mistake silence for strength. I think you should ask yourself what is it about you that's attracted that person, not necessarily about what they've got. Yes, I'll come to that later because it depends on your previous experience of relationships, which maybe gets you on a rebound for this.*

The things that attracted me were escapist stuff, like he'd go walking off up mountains and introduce me to things I'd never done, and I thought that was all wonderful because it was a different way of being and you mistake a lot of the stuff they do for other things, through no fault of your own or theirs and you have to say what it is about you that goes to them not them the other way. Yes. My partner had such a confidence about him. When I first saw him he was 6'5" and had eyes which I can only describe as piercing blue. He came over from another side of the room, everybody else was sitting in groups, he came over and walked to a girl who was heavily pregnant and made a fuss of her - I thought he was her partner. Because he seemed confident - it didn't bother him that anyone was watching him - and he made an impression and I thought he was a smashing fellow.

I must point out that the person may be very compassionate for something he can physically see, but anything abstract mentally they are very ill at ease with. In other words with a pregnancy you've seen other people relate to a pregnant person, you have the script in what

to do and it's physical and you can relate to it, but when somebody's talking about their inner feelings then it can be difficult for the person to be equally compassionate and concerned for a mental state rather than a physical state.

I'll go through a few more. Shared interests. Sometimes they've met on expeditions somewhere. In other words they both share the same hobby and so it's a meeting at that level. It's also the degree of adulation. It's almost as though that person is besotted by you which can be very appealing to have somebody who's always there and so attentive in many ways and remembers so much about you. It's the degree of adulation which is perhaps a little bit intoxicating, that there's that degree of interest.

Once we got married that stopped.

With the newsletter I've had quite a lot of letters from people and they seem to get married on the rebound - after a stormy relationship, a difficult marriage or even a very good relationship which didn't work out for some reason, and then they meet this quiet charming person and think its going to be OK.

I think it's the absence of signals, the person projects on to that person what they want to see and that person doesn't really show the real person underneath I think really until you're actually married, because in the lead-up to it they're acting in some ways of what to do and once they've won the prize, that's it.

It's also fidelity in relationships where the person seems to have a degree of shall we say interest in one person, but I'll come later on to many with Asperger's syndrome syndrome don't go beyond the emotional maturity of a teenager and many of their relationships are like teenage relationships, and some that I meet in their thirties and forties, or fifties, they're like a teenager in a number of ways. I know there is a comment that some men never grow up but some do, but here it does seem to be that the person is an eternal teenager in their relationships.

My husband has an infatuation every month with a girl wherever we go, and he'll come home and tell me all the details about her, what he likes about her, how lovely she is, what she does, and I get this every month. The whole detail. It kills me because he is so honest. He doesn't have to tell me, but he does..

Yes, it's like a teenager going from one relationship to another. Also can be a pillar of the community in a number of ways. Can be creative in their work and have very good career prospects - so you may think this is a good ticket for a nice retirement - this is somebody who's obviously going to earn lots of money etc. Can work very hard, a workaholic, in some ways especially when kids arrive, it's an escape from the issues. I'll come to that later because what we are talking about today is how to develop a relationship with your partner. One thing we've not investigated and must be covered is their relationships with their children, because it can ruin the childhood of their ordinary kids, who resent their lack of love and affection, they're very black and white in which kids they like and don't like, and

one kid can have total adulation and the other one they just don't want to know and there's terrible rivalry. There are adults I know who've had a father with Asperger's syndrome who have had to have quite extensive counselling because they felt that their father never loved them, never showed affection, they could never live up to their expectations and that has corrupted many aspects of their subsequent relationships, so as much as we are talking today about how you help them in their partnership, how do you help them become a parent, because that can cause major difficulties in a number of ways.

Something that people have written to me about is that initially early on in the relationship, they thought their partner was very brave because of this sort of lack of respect for social conventions, so that sometimes you think someone is very brave to have said that, wish I could have done that, and that's how it appears, because it's a thin dividing line between being inappropriate and embarrassing.

And audacious in that way. When you say brave, there is another issue, there are quite a few with Asperger's syndrome who like going into the military because it has a clear structure and in their military career, like Wittgenstein and others, they've won medals for their valour in not letting sentimentality and their comrades get in the way of the objective. Sentimentality just goes out the window and they will go for that objective, so they can have quite illustrious military careers in a number of ways and become, it's usually in the army, some in the navy, quite usual in the airforce as pilots.

Of course the routine and discipline and so on and the rule book.

Yes, what's required, a clear hierarchy, the respect, all those sorts of things are there and this is where Asperger's syndrome may be an advantage in times of warfare is that the person is clearly going to get that objective where others would think twice about this about social emotional consequences etc. No they just go ahead for it and if they succeed they get the medals, if they don't, they're killed.

I remember dragging C back, this was when you were talking about what attracted your partner, there was a fight and he heard this person's head crack against the wall and people were drunk and he was about to launch in and see to this person who was on the floor and in fact we pulled him back, because we thought he would be launched on, and I thought that was really brave, and it was only later discussing the incident he hadn't realised his own potential danger.

It's not reading the cues that others would take in, it's only seeing someone's fallen, it's like tunnel vision, not looking at the big picture and the consequences of planning that if I do that, that will happen, he'll do that, he'll do that, don't do it.

They don't see that.

No, it's being impulsive and looking at that tiny event. It may also be similar characteristics to a parent, and I do find some ladies who marry a man with Asperger's syndrome may have

had a father or their own family members with Asperger's syndrome. Have any of you picked up that? *Yes. (show of hands)*

I remember saying when I was younger I will never ever have anyone like my father and my partner is so like my dad - they're so alike.

This is where it's interesting on the genetics because there's almost a selective arrangement that some ladies will marry somebody who reminds them of the genetic aspects within their own family. Some in recognising that have learned how to cope in that type of family setting, and so they do that with their partner because they're familiar with that atmosphere and it's a "normal" relationship they're most unsure about because they've not experienced it in their own family life, so they've gone from their family life to create another one that's identical to what they've had.

If you've experienced violence and this person is not like that it's absolute heaven.

Yes, although I will add for some partners it comes as a shock that person's temper at times - because what they previously thought of as very even temperament will suddenly have these explosions that if you've never seen them before you wouldn't think was part of their character, and other people may not see them until something apparently trivial such as the sauce bottle's in the wrong place and there's a huge explosion and then it's over.

My husband was so gentle, but when he lost his temper and brought the breadknife onto me when I was lying on the bed - I never suspected that.

My husband this year attempted suicide, we've discovered now that he has been depressed for about 7 years, since he had to cope with redundancy But now he's depending on himself rather than me.

Psychologically there's either an internalised or externalised depression - if it's internalised there's a risk of suicide, if it's externalised the risk is explosive anger towards other people, and that's what can get them in trouble with the police, their partner, all those sorts of things if its externalised. In fact they're often looking at anger management as part of the treatment of depression.

Choice of Partner

Moving on, we then come to the issue of the choice of partner and I have a few thoughts on this and I would welcome your comments. If we have a continuum of social emotional and empathic skills, if you take autism and Asperger's syndrome as the extreme end, the person tends to marry either somebody at that extreme end, in other words somebody of similar characteristics but an introvert, may also be interested in entomology, or somebody who is also a bit shy who also doesn't like lots of people coming round, so in other words like marrying like.

Or it may be marrying somebody who is at the opposite end of the continuum, and that is often the most common one of marrying somebody who is very social, very empathic, very kind and very caring, and it is two contrasting characteristics - the opposite end of the spectrum. They "mother" their partner. The third possibility is that there may be a dominant submissive relationship or an arranged marriage, where the person may have a certain degree of arrogance and difficulty relating to others, may have an arranged marriage, through the Philippines, Thailand, etc.,. You may not know somebody but from my own clinical experience this may be the case, and sometimes then subsequently having an autistic child. But sometimes it may be a relationship that's arranged or a very dominant submissive role, where the person with Asperger's syndrome is very authoritarian but marries somebody who by nature is a very submissive person for a variety of reasons. What are your thoughts on that, how does that fit, there are basically three types..... ..

I didn't understand, well I do now, but for years and years I just didn't understand my husband and his reaction, or lack of reaction to all sorts of situations. His passivity and appearing not to care, whereas I cared so much, and I think he made me do all the caring and worrying for two because he was just out of it, he just withdrew in any situation which was stressful to him but just normal really - I didn't like it. It's almost by default somebody's got to do it, so in you step to deal with that. But its very broad, solitary shoulders that takes on all the weight.

What I find is that you got more than you bargained for - I would say that my husband and I are opposites and we counter-balance one another very well, but I feel that I carry him in lots of situations and he doesn't do that for me, so I am a very motherly person, but I definitely got more than I bargained for and I didn't expect to mother him - I find that very difficult.

A hundred years ago that was the role very much of two distinct people, that the male's role was to work and to come home, and the wife was at home and did everything, but now we have a much more equal situation where women in particular expect their partners to be their friend as well as their marriage partner, and here the person with Asperger's syndrome finds it very difficult.

That's not so much a problem because I don't class myself as a working mother although I do go out to work, but it's very ad hoc and I like being at home and I like doing that kind of thing, so I would put myself in the traditional mother at home role which is fine, but it's the mothering of him which I hadn't at all bargained for and I do find that instead of four children I have five.

About the job, I think that one of the things I've found very difficult is there have been a number of times when things have gone wrong for C, sometimes it's his own fault sometimes not, and it's sorting that out... .. if I could just send him off to work and feel confident he was doing that bit right, the rest of it would probably be more manageable.

It's the responsibility of going through that and being the only person they know who can rescue them. It's not shared by anyone else because it can't be done by colleagues at work or other family members, you're doing it on your own in supporting that person and if you've got other kids as well, it's dividing your loyalties, especially as your partner may be very jealous of the time you spend with the other kids.

With arranged marriages, they can understand it's a contract, this is the deal, I will provide this, you will provide that When as a non-Asperger partner you marry an Asperger person you're not aware of it, it's something you're not initially aware of but when you move into it you expect to change roles, mature, do things this way, and they can't, and then you start to kick back against that...

My husband does want an emotional side, but I'm never quite certain, it's like you've got a script and I haven't got the script so I'm not quite sure what my words and actions are supposed to be because they don't conform with whatever that's what the idea is, so I'm completely in a fog.

When we're actually working with kids with Asperger's syndrome, we're working on scripts for them of what to do, but in fact that's creating a rigid script if you're not careful.

That's all right if they share it with the person they're supposed to. Otherwise they keep going on. What they can't do is change track, in other words they just keep repeating the same thing and they expect you to give the answer that they want. Other marriages are just as scripted

I think you've got to look at it in those terms. I must admit that some of the most successful relationships I've known in Asperger's syndrome have been where someone has married their own personality type, and I know Liane Holliday Willey who wrote "Pretending to be Normal", her husband has very similar characteristics to herself so that can work - the expectations are similar, and so that's fine. The difference is when the person at the other end wants a bit of movement in that direction and if the person with Asperger's syndrome doesn't want to move, it's very hard to get them motivated.

Do you find a difference in the culture with different generations, because certainly in the forties and fifties, perhaps even up to the sixties it was still our culture that the woman waited to be asked. If you went to a dance or anything you waited for the man to show that he was interested in you before you reciprocated. I know it's not like that now, but for anybody who grew up in the forties and fifties their husband would have been the one who made the first move, let them be aware that he was interested in them, so it would be what attracted him to you wouldn't it? I think in our case, it was just what you said, that because I'm seven years older than him and I'd just come back from working abroad, because I've asked myself this so many times, and I think to him I appeared to be a tremendously sophisticated worldly woman, which is what he wanted to be and he wasn't, he wanted to go travelling around the world and he didn't know how to, he didn't know how to go about it, and I think that was one of the things that attracted him and also that I was so

managing and so capable and very caring and things like that. Do you find that in women nowadays in younger relationships, that this isn't so? I mean nowadays women don't wait for a man, do they.

With Asperger syndrome what they would do is either have somebody they had an obsession with, or they had a very clear image of who they wanted to marry and kept going until they found that person and then made sure they got that goal with determination. Here for some of the relationships now, it's the woman, the partner, who has made the first move in a number of ways, and it may be that they then only later on realise that what they initiated has not turned out the way they expected, and they feel bad with themselves that they've made the mistake of not reading the cues earlier on.

Do you find that modern relationships last as long - most of the ladies here have been in relationships for many years - have you found that they get out quick when they realise there's something wrong or do they ...

I think they either break up very quickly when that partner realises they've made a mistake and get out fast, or the other thing is, and what's always astounded me, is the ability of their partners to keep the relationship going. Where others would have given up - it's that tenacity in the relationship that the person has tolerated their isolation, their lack of support, all those sorts of things with a degree of stoicism that's remarkable, but I think that is going over time and people are more likely to pull the plug out and end the relationship. Previously where to be a single parent was socially unacceptable now it's becoming almost, well it is commonplace, so I think more women are prepared to end the relationship, but one thing I do find with wives of husbands with Asperger's syndrome is their reluctance to end the relationship, they really are so devoted to that person, but I think it's also a bit of emotional blackmail because they know if they left, how would that person cope, that makes it very difficult for them to say goodbye.

Family Life

How many of us here have children - that's the other thing - if you've got children with Asperger's syndrome too - you're not coping with life anyway are you - and to leave and to take another child with you who has got Asperger's syndrome is just impossible so you stay, you're in an impossible situation - you're terrified to do anything, so you just sit on it basically. Yes. In fact my relationship's come to an end because my son's been in residential school, he's coming home, and I knew I couldn't bring him back into what we had before because it was too stressful for him - and I thought, no, somewhere along the line it's got to end, I couldn't cope with his depression and the situation with his father, he just couldn't cope with it, and I couldn't cope with him in that situation. He was away at residential school? Yes. Are you happier now? Yes, yes, because a big pressure has gone, I was spending a lot of time trying to keep them apart because my son is a completely different character and he found it very difficult to cope with his father's attitudes because his are so completely different and because of the schooling he'd had he had ways of coping with a lot of the problems and he couldn't take it that somebody couldn't cope with

the same problems - he can cope with the situation - though you can see the thought processes going through a script as you say, to work out how he should respond - he can do it but he found it very difficult because his father couldn't.

Can I add one thing I've noticed is if there's been a father with Asperger syndrome with a son with Asperger syndrome, invariably there's been enormous conflict between them. You would hope that they both came from the same planet that they would understand each other but in fact they often push each other away. What is interesting though I've noticed is sometimes with a mother with Asperger syndrome, with a child with Asperger's syndrome, can have a good relationship, that's the experience I've had. It's just that dads with Asperger's syndrome have great problems coping with sons with Asperger's syndrome and there can be major fights between them, but if mum has Asperger's syndrome with a child with Asperger's syndrome there can be a much better rapport.

We have five children - I'm sure I've had all these children because I needed the love that I didn't have from my husband, and the children are aged from 19 down to six, the youngest one is AS and that's how we found out, but since he discovered one of them had problems he's been wonderful.

It was because of our Asperger's syndrome son that we think my husband has it.

Yes you're lucky in that sense because I know of quite a few who have had major problems, the wife has been literally standing between two characters who are trying to slaughter each other and so an added responsibility as a go-between. We do find that if there is one child in a family with Asperger's syndrome that other children from that relationship may have what I call fragments of Asperger's syndrome, not enough for the full diagnosis but the diagnosis is made on various pillars or components, and some of those pillars or fragments may be there but not enough for the whole thing, so it does really affect the dynamics of the relationships to an enormous degree, but often the partner is coping on their own, as I'll go through later on, the Cassandra Phenomenon where nobody believes the partner what they're going through.

Lunch break

One of the issues has been what we call now the Cassandra Phenomenon. The partner recognises that their husband or wife with Asperger's syndrome is different and nobody believes them. Cassandra in Greek mythology had the gift of prophecy but the curse that nobody would believe her, so quite often as a partner you may be describing these things but when you go to professionals your partner may know intellectually what is the right answer to give, acts or makes a façade, and other people may think that you are lying, that you are creating this, that it is psychological or whatever.

I would also add that for some professionals, there is the Cassandra Phenomenon, that when they work in this area other professionals don't believe them. This is one of the situations

that Venetia's got because she's trying to get off the ground professional psychotherapy and support for couples where one has Asperger syndrome, but is having enormous difficulty convincing her colleagues of this area, so it's not just you, it's for those professionals who recognise it actually being given credibility by their colleagues.

Venetia, can you describe a little bit of what you do:-

I work as a family therapist, though I started off as a GP, in a family therapy department. Over the last year I have been increasingly diagnosing people with AS. Many of these men have been in the psychiatric system for some time or have had counselling that although good has failed to meet the issues. The diagnosis has largely been a relief and has enabled a new sense of direction. I have just finished working with one couple who feel that they are truly happy and they wished me to relay this to the Coventry meeting. In being happy they have defied all sorts of unwritten rules. They are retired and in their 60s, but are not inflexible. The husband has learnt to be empathic. His wife has learnt to appreciate the benefits of her husband's busy, intelligent mind that likes to have everything organised. She has found some benefits to AS. She has really good meticulously planned holidays. What has helped working with them has helped with other couples too.

Putting AS sitting in a spare chair in the room meant that he described it as being a little version of himself, something he was completely familiar with. She described it as a tangle of wires that she couldn't sort out. He then became very energetic in helping her to understand what went on in his mind and so she learnt not to presume that she knew what he was thinking or meaning. Another couple described their different perspectives in life as being like a vase made of oak (his) trying to have a marriage with a vase made of fine porcelain (hers).

Both of them found visual descriptions of the problem helpful. The notion that AS was like an umbrella under which their family life had sat, helped them see the shadow that it cast. It helped getting family life from out of the umbrella and getting the AS in a different proportion, with them both relating as equals side by side. They then had a phrase to use to highlight a sense when the umbrella was being put up and something aspergery was dominating life again. I have found ways of drawing empathy on my whiteboard. To learn empathy the husband has to be curious about what might be in his wife's mind. Curious that the world may not be as he thinks it is. He also has to be courageous to learn to speak a new emotional language. He has to combat fear, uncertainty. He has to learn the colours of emotional relationships rather than retreat into monochrome.

Drawing family trees was helpful. This highlights the patterns of relating through the generations. It also helps to show male and female ways of doing things. Several families have begun to talk to other family members about AS.

Using metaphors that are congruent with the experience of the AS sufferer are important. They can understand relationships better if described in terms of the working of a car's engine. That if too much money is spent then there is no fuel to run the car. If there is no

praise then there isn't enough oil so the car squeaks and gets hot and may seize up. With a family where I worked with Tony where the AS mother was a chemist who couldn't understand the effect of her rages on others, we described her as like a catalyst. If she came back from work hot then all sorts of chemical reactions and upsets would happen around her. It was important that she came home from work cool.

Working with the children has been revealing. Children learn many coping strategies to survive and get a bit of what they want. None of the ones I have met have been happy and bouncing with self-esteem. Some have been damaged, some are resilient, all have been keen to talk about their experiences given a confidential space to do this in. It takes a while for them to realise that the stories they have to tell are important and matter.

There have been problems with colleagues, as Tony says the Cassandra Phenomenon is very evident. As AS is not a mental illness, psychiatrists aren't interested and fail to see the relevance. Several times families have got caught in the crossfire and I have had to think seriously about using the diagnosis in these situations. Trying to work without naming AS is possible but unnecessarily complicated. I am hoping to have Digby Tantam come to the hospital to talk. Psychiatrists will come to listen to psychiatrists. None came to listen to Tony when he was in Carlisle (except the child psychiatrist who specialises in AS) though the auditorium was packed and we could have sold as many tickets again!

I do think there is hope. My families with AS have provoked many more creative ways of working than my usual run of the mill work. I am sure there are lots of other nuggets of therapeutic creativity to be found.

Does it exist outside England?

I travel all over the world, it exists in all cultures, but one of the issues is that there is none so blind as those who won't see, and one of our major difficulties at the moment is that the DSM 4 and ICD 10 which are the main text books for diagnosis, were based and written before we really knew much about Asperger's syndrome, and made assumptions that we now know are not true, but the view has been that in DSM IV, it's like Moses and the tablets, that's it, you can't change it, when it was made as a guess, for example like language development or self-care skills or all those sorts of things, when it was written it was a guess. We now know that those features are much more flexible and different components than we first thought, but that if you look at those pure criteria, you will very rarely diagnose somebody with Asperger's syndrome and that's been a major stumbling block for the development of services for such people, is actually finding a label, if they don't have a label I'm afraid there's usually no services - one of the advantages of that label is that people then know where to go to get services, so Venetia is trying to start a service for couples, but as much as you're having problems convincing professionals, as a fellow professional she's having exactly the same problems.

Are you going to write a paper Venetia?

I've got one half prepared to write for a Family Therapy Journal.

They don't have to be physically violent to bully you though do they, they can be verbally abusive as well. And manipulative in their behaviour, that's another thing.

And financially abusive if they control the money. One thing is they've not really learned the art of negotiation or gentle persuasion, they've always learned confrontation and somebody else is nice and backs down, so the view is to use emotional blackmail of a tantrum or violence to get what they want, but what they've not learned is how to negotiate with people in a subtle more effective way. It's like walking on thin ice all the time, you're very, very careful that you don't crack it and upset them. So there are problems.

Is there potentially a problem, my husband is passive and our son is active, my husband has taken that on board and is perhaps giving in too much to the little one and I wonder if there are any steps we should take, I just wonder if we are creating a bully in our youngest child, he's so active, he creates such a big thing in the house, my husband's understanding of him is brilliant so it's wonderful ...

In a way when you look at the passive group they are more likely to give it a try whereas the active group are going to be more resistant, they more or less have a façade of I'm OK there's nothing wrong you've got the problem and that's what in the active group you've got to work on. What you have to do if the negotiation has occurred, you have to say well there was another way to do this, which may be after the event, and what we do with the kids, the teenagers, is we start talking to them about United Nations diplomats etc and say this is one way of solving the problem which is what happened but let's go back through it, there were other ways or other things you could do, because if they have only one way of solving problems, which is confrontation, argument, blackmail, then you say well look, you can get by in life by other subtle means, which are better for both of you, and you just say that there are alternatives you can go through with that person. There is plan A and there is plan B and they only have plan A - it's like that toolbox has only one mechanism - what they need to learn is if this doesn't work, there is an alternative you can compromise - compromise - you can back down, you can save it for another day etc., you don't have to keep going, because otherwise you're sort of blinkered.

I'm a teacher and avoiding situations worries me, but we do this, we treat the little one as if he were a problem, because we avoid all the upset we can, we can't of course being serious, but we try to, that's our aim, and the issue worries me.

It is an issue because I think over time they're going to have only one way of coping with things, where other kids have the plan B C D and E of what to do, but if he's only achieved things in life through you being flexible and compromising, he's got to do that too. You start on some minor things and build up - I'm glad that you're aware of it - but you need to start working on it otherwise later in life that becomes a set way of problem solving.

On the topic of problem solving I want to go through some issues now of what you found worked or not worked. The morning in a way was basically describing the issues, as to why they occur - in other words there's a legitimacy to the issues which you face, but what I want to do now is to use this opportunity together to go through some of the things that have worked successfully. Now if I go through the possible agenda, one is a difficulty for the person with Asperger's syndrome if they're a parent is understanding natural childhood abilities and behaviour, where you have to say, but look he's only four years old you've got to expect that of a four year old, or often they don't know how to relate to their partner or their work colleagues they also don't know how to relate to their kids. Is there anything you've done that's helped in this area, have you found anything that helps the person with Asperger's syndrome understand normal child development and what to expect from kids?

If only I had known! This was a great source of tension and unhappiness when M was growing up, and though I did try to explain that it's normal for small children to have tantrums and to be disobedient because they're testing us ... I don't think he understood really.

Many of them had a very different childhood and had been switched off to what other kids were doing, so it's completely new territory, the only thing I can think of is almost to throw the book at them of child development, to say this is what you expect of a three year old, this is what teenagers are like.

I used to do that. I used to wait until they were all in bed and all was quiet, and somehow without being aggressive talk to him teacher to pupil, it happened to be my field so I was on safe ground, about child development and being a very intelligent man he took it very well but it had to relate to the situation and be very cut and dried and simply factual.

It's appealing to the strength in Asperger's syndrome which is logic, not empathy, but logic. I've found interestingly that they accept what's written more than what you say, so if they can see it in a textbook they believe it's accurate. I mean with the kids, there are problems that they believe fiction is fact and videos are documentaries, they're fiction but often when they read it, they will accept it more than what you may say. This is why with kids we use social stories quite a bit - it is that they will believe the written word but not the spoken word quite often.

We've introduced the idea of other people's children, having other people's kids in to play and seeing this happens all the time and because I noticed over 20 years my husband had problems with this, I have had a lot of situations where I have been running workshops for children and this had greatly benefited him, because he sees all human life pass through his own kitchen and he's been more prepared to accept that that is what children do.

One of the things I do with kids is what I call an anthropologist in the classroom, that is to sit in a corner with the kids, watching the other children in the class and a bit like David Attenborough is talking to the child about what's going on - and say Rebecca's coming up and she wants to join in, see how she does it, she looks, she waits and then she's in, now let's

look at the way the Dean comes up, oh dear what do you think. It's almost as though they need somebody to take them to a pre-school and say look this is what's going on, they're not miniature adults.

I think they need to see something tangible, if you talk about it again it's abstract it doesn't seem to get in but if they read it or see it, it adds a degree of conviction, so if you can point out - this is what they do, they want the tricycle, they push the kid over and take it - that's what three year olds do.

[Discussion here about how to get partners to listen to and believe what you say]

Can I just reinforce one point, the need in the relationship to have a third party to monitor that and I would use the analogy, it's like having the 10,000 mile service in the relationship. You need to go in to the counsellor to check what's going on, because there may be something that needs draining, changing, modifying or whatever. One of the things we use a lot in Asperger's syndrome is metaphors, they often talk in metaphor, they relate to metaphor, so if you can create either a verbal metaphor or a visual metaphor, for what you're going through, they'll often understand it much more easily, so we would use it like going for a car service.

With Asperger's syndrome they don't seem to learn by their mistakes. If there's emotion involved their thinking processes, their memory processes, because when we do any act, what our minds will do, our frontal lobes will do, is look back and it's almost like a retrieval of similar situations, what were the results of those situations to bear on this as to what to do, and if there's no memory in relationship to that, then you're going to repeat the same problems, it's like if you touch something that's hot, next time you see that your memory says it was hot don't go near it, but if you haven't got the memory it was hot, you'll touch it again.

There's also the problem with generalisation, talking about hot things, they know the cooker's hot, but they may not know that the gas fire's hot or a match is hot.

Yes and this is where it's very concrete pedantic learning. I was doing some CBT with a 14 year old with Asperger's syndrome who had a love/hate relationship with a three year old sister, and the parent had always said don't hurt your sister, because she could get very angry with her, and one day she got angry with her sister, took a cup to the hot water tap, filled it up and poured it over her sister and then said but you didn't tell me not to do that, not to pour hot water over her. You said don't hit her, don't smack her, don't push her down the stairs, she was happy to go through everything, but you didn't say don't pour hot water on her - you've got to go beyond the words, it's the actual hurt that counts.

I think part of the problem is as well our response and how long they take to respond. If you look at the emotional hurt, if I stand back sometimes if I've been hurt and look at why he's done whatever he's done, there's been no intention to hurt if I look back and see why. So that's one problem you've got to be able to stand back and look at it and the other thing

is quite often if you talk to them you will get a response, but it can be delayed by 24 hours. I mean I find with C I might tackle him one evening, I want a response there and then, you know the hug or whatever we want and instead I'll get perhaps a cup of tea in bed the next morning, but it's that intervening 12 hours.

In fact often what you've got to do is plant the seeds, not expecting an immediate answer, just plant the seeds and wait, because cognitively they've got to work it out. If you present it to them, their first thing is to close down, denial, or whatever, but if you let them think about it and then wait until they've worked it out cognitively and then they may respond appropriately but they can't spontaneously

True but I think the problem and I think a lot of people here will identify with this, in the intervening time it's just awful for the partner because it's an abnormal response.

Yes but sometimes it's planting that seed, in fact what we're doing diagnostically in the diagnostic process for adults, is we will use some of the same questions we would ask the kids and technically they will give you the right answer, but it's the time taken to do it, not whether the answer is right or wrong, but instead of it being 500ths of a second it's 5 seconds and you can watch them go and they'll give you the right answer, but it's done cognitively, not intuitively.

I find it's avoidance of the actual issues. They think if they give you enough time you'll forget it - because my husband does deny everything, if I'm upset because he's come home from one of these women - he'll deny it - but in a month's time he'll say well yes I did do it and I denied it because I didn't want you to know that I knew it was wrong - it's an avoidance of the issues, they do know right and wrong - well mine does - he knows he denying it - so I don't have an argument about it.

One of things I'm going to go through today is lying because that is an issue because often it's not the deed that you did but the fact that you lied is more important but I'll come to that in a moment.

Can I just ask something about children - my children are teenage now - so the problem isn't there to the same extent - but when they were small because he didn't know how to react -in fact with the first one, he denied him for quite a while and wouldn't come to the hospital when he was born and so on, but then he used me as his model and I would shout at them for doing something and then if he was left alone with them and he had to handle something, because I'd been quite severe on one example for something that I knew warranted being severe, he would use it inappropriately and he would shout at them for something very insignificant, so it got to the stage where I had to take 100% responsibility and never leave them alone because I knew he couldn't respond appropriately, and with the result that now I have teenage children I have an elder child now who perceives me as being a very dominant and control freak personality and I find that a problem - it's not a problem in the same extent but I want to justify myself and say I'm not a control freak.

I think this is an important issue because you had to change yourself to accommodate the family circumstances and deny the real you but that's what people see, it is what you're having to be, but it's not you, as much as the person with Asperger's syndrome learns to act, you have to act in that culture and that means that you've got to give up who you are and what I'm going to go through later on is that you need to escape, you need the opportunity to get out at times and be yourself with your own friends, your own social life, so that this isn't totally an imprisonment in that setting.

Yes, but if the ship's heading for the rocks and the captain's missing, somebody has to grab the helm.

Dealing with the children, most of the time I am the one who disciplines them, but with having the two boys the way they are and the way S is he didn't always realise that they were doing things and making the same sort of same comments that he makes. When they're winding each other up and getting worse and worse, S can be sitting there watching me trying to deal with it, and I say can you say something and he'll say what you've taken 10 minutes and they still haven't sorted themselves out, I'm not here to back you up. How do I get him to realise that he doesn't let it get to that extreme where he finally snaps and maybe wallops them harder than he meant to, which happens, and I'm standing there thinking quick kids get behind me, hit me rather than them, because he will get very angry, how do I get him to start intervening sooner, or do I just ignore that he's there and do it myself?

I think there are a couple of things, one is the suggestion we've had before to talk when there is no emotion in the situation, because once the situation gets emotional logic goes out the window and logic is their only great strength, and that's when I think you need someone like Venetia or myself to talk to, for both parties.

You can't get logic involved when it's happening at that moment and things are getting worse and worse - you can't just say let's sort it out - I'm sitting there a nervous wreck.

What have you done to resolve that, when there's obviously an argument between the partner with Asperger syndrome and other family members, what have you done?

Time out - go into another room.

Once there's emotion in the situation, there's going to be no constructive approach, so basically you've got to deal with the emotion and may be the only way to deal with the emotion is to separate and when people have calmed down, then we'll work on what's going on etc, but that's when you can separate or people are willing to separate. But there can be difficulties with that.

If there is anybody else around when a situation starts it's worse for him, he can't act that out in front of other people, it seems to get worse for him if there are others around to watch it. It's OK if it's just me and him and perhaps the children to have a go and try and

sort things out, but if there is another person around it seems to shut him down completely, he can't be witnessed.

It is normal for there to be arguments between fathers and sons, it's part of the normal relationship isn't it, conflict of interest, but my problem is that my husband is too passive to argue and he couldn't be bothered to argue so my son more or less became the dominant one which was very wrong. The dynamics were awful. He was trying to take over and be head of the house because my husband was so passive, and he let him. He would sit in the morning with his briefcase waiting for my son to say he was ready for his lift, instead of saying come on, it was up to him to call R down. But he would sit and wait and fiddle with papers while R took his time and then stroll downstairs and deign to get in the car, and no matter how much I tried to explain it was all wrong, the dynamics were wrong, that he should be chivvying R up, and then R would come this dominant act with me, Mum, because he was getting away with it and I wouldn't have any of it, so the conflict was all between me and my son because I had to take over the father's role.

Anything else on that - standing in the middle - anything that has helped?

Well we didn't know what was the matter with my husband until my son was diagnosed - I have three older daughters and the son is the youngest and he is the one where conflict would arise because his behaviour would be typically autistic, and my daughters got very strong and very good at hiding my son's behaviour, they could keep their father in another room and talk about anything, but they could keep him away from tantrums, they were dab hands at doing it, because I could then handle it and so it worked like a team - one would be keeping him occupied while someone else was helping me deal with the other one - so he didn't know - I reckon he didn't know of the majority of the tantrums my son had, because the girls just automatically clicked into this mode and they would keep him away.

That's good, if you can get the other kids who know what's going on, to act as a way of dealing with the situation but it does give those other kids quite a sense of responsibility, of almost living in fear and trepidation of their father because of the tantrums which can lead to enormous resentment.

The difficulty was the daughter immediately above my son used to take the blame sometimes because she knew he couldn't help it, so if my husband found out and he was having a paddy in one room,, she would take the blame, more or less suggesting that she had caused it. In fact the relationship between her and her father has always been appalling. But she knew it was wrong for him to be punished for what he couldn't help, so she would just take the blame, she used to do it repeatedly.

This is where family counselling is often needed and why we have sibling groups for Asperger's syndrome, and a lot of our support groups for parents will have sibling groups, which allow the siblings to understand not only how to cope with their sibling with Asperger's syndrome but how that's affected dad's relationship with them, and all those sorts of things, so that's a useful way of getting them together. My wife has a sister with

Asperger's syndrome and has run some of those sibling groups where she's talked about what it was like in the family in that situation.

I find by letting them talk honestly to me when he's absolutely driving them mad, to know that they can just say it without feeling as though they're being disloyal to their father is a help. They can actually honestly come and say "Dad's driving me mad doing such and such .." and I can say you know he can't help it why don't you just go and - they can actually say it without pretending it doesn't exist. The same with their brother, they can say it without having to pretend the whole thing just doesn't exist.

That happens with some families I am afraid. The next one is rivalry with the children - in a way this is where the person's level of emotional maturity may be comparable to their children. Do you get these features? What do you do in that situation?

Go mad - or smoke a cigarette.

Gin and tonic perhaps?

What can you do? If only there had been some support when my children were growing up - they're adults now - all these traumas have more or less gone, but there was no support then, they're 28 and 25 now, but I knew there was a lot of stress and tension and there was just no-one to appeal to.

With me it's always been the time the children wanted to talk about something that was troubling them was when they had gone to bed and they can't face it on their own, but that was always been the time G would say why are you always staying talking to the children you should be downstairs talking to me. The rule is, no talking after.....

It's like being back at boarding school! Which brings us to the next topic which is regimentation, where if you're not careful the whole day of routine is too ordered.

Can I ask a question? We were talking this morning, my husband has parents who we now recognise as classic Asperger's syndrome people themselves and have had a wonderful life because they really enjoy being like that. He was obviously attracted to me because I was totally different from them, and he wanted another kind of life and he thought this was wonderful and we are looking at the fact that he's adapted incredibly well - is this because our style of life has had to be chaotic over the last 20 years - he's been a shift worker and I've been a teacher, I've done a lot of work at home, there has been a lot of invasion of our home, he has had to either grow up and join in real life and the children have all been very well balanced to all the changes and stresses, or he would have left, has it been good therapy? I wonder whether we should have done anything different?

The risk is if you're not careful of becoming too regimented to stop the tantrums, which often is the child's or the adult's, only way of coping with displeasure is to do that, so if you can ensure that there is no negotiation - it is chaotic we are going to have to change despite

what you're going to do, this is what's happening, that's a very good thing if you can, because otherwise everything freezes according to that routine and the difficulty with autism and Asperger's syndrome is that the more it's become a routine the harder it is to change it - if it never becomes a routine, it's when you've done it two or three times the same way, but if you do it differently almost each time, you're OK, basically showing that you can survive if it's not at 6 o'clock exactly, the world will not collapse. You have to do it deliberately - in a conscious way of going to the shops a different way, different meals, etc - otherwise it will be the same meal on Tuesday, you will freeze yourself.

That's how he was brought up and I reckon that's why he had such difficulty when we first married because he had 20 years of that, everything was labelled.

You can spot an Asperger house! It depends on the chaos - one person's tidiness is another person's mess but sometimes with the kids with Asperger's syndrome it's that their room to others looks untidy but to them it has a logic of where everything is placed and they know when it's moved and some eccentric adults with Asperger's syndrome, when you go into their house, there are things that they can never throw away, that are catalogued, and so it looks untidy but it's just that they can't throw anything away and they have to know where everything is. When you're talking about those issues, make your voice devoid of emotion, just pure logic and just reply it's not negotiable. Whatever you do, whatever tantrum, it's not negotiable.

Another issue is money management, where there can be a degree of Scrooge-like qualities, unless it's the special interest. With the special interest they may spend whatever last penny you've got - do you face those issues? Again, what do you do to cope with that?

A complete lack of understanding as well with my son-in-law over what a credit card is, I think he thinks it's a present, my daughter had to re-mortgage their house, he ran up debts of £11,000 and she had to re-mortgage the house to pay for this, I nearly died, and she cut up his cards and gone over it, tried to explain in detail how banks work. I have heard other people say this as well, so it must be a problem for a lot of people. But for some their money sense is just not there.

My husband's not Scrooge like in any way - but he's no concept of the value of money - if he sees something, it might be a new house, he'll say I would love that, that's where I want to live, lets go and see about it, and I'm left there with sleepless nights thinking well where are we getting the money from, he doesn't worry about it at all.

All the people I think with Asperger's syndrome have some element of Attention Deficit Disorder - and it's that sort of impulsivity and lack of planning. When advertising for say a Selfridges card says "Want it - Charge it" or "Just do it", and that's the view, that's what they are after, is people who do the spontaneous buying. What you do is you think beyond just the purchase, you think how are we going to afford this and all the logical components. Here the person is just living for the moment and that causes major difficulties with money management, but also in their jobs too because sometimes when they are in charge of

finance, they can lose their job not because of embezzling money or anything like that, it's just poor money management, when they're in charge of a budget.

He knows the rules are that you have to pay the bills, but when he's got his own money he's terrible..... I think that your daughter was right, cutting up the cards..... I open the post so I can keep an eye on what is going on..... You've got to..... I live with Scrooge, so for anybody else who lives with Scrooge, he loves his great financial sheets across the computer and everything, and I have a little photocopied spreadsheet for each of us. I dutifully fill it in, it has columns, what I've done is engineer it, I'm a dutiful wife and I sit and write it all out beautifully and total it all up, what I don't do are the final sums because I know that my pension does not cover all the household expenses, so at the end of every month I know "I have overspent". All I have to say, because I have done it visually and because he is an absolute sweetheart, is I just say "right, I think we need to top up the household account, dear". I don't do the final analysis, I really can't be bothered, because I know in my head that every month I shall overspend because I don't have enough money, but somehow it's my money that always gets used and I have to ask him for some more, but he's so sweet about it. I think what I'm trying to say is be seen to be writing it down, be seen to be like his mother was, careful with your money, I'm the total opposite to his mother I'm a wild spendthrift in his eyes. Other people would be appalled at what I actually live on.

You're bolstering his self-esteem aren't you, you're actually helping him to feel he's in control of the situation.

Yes, and it is making that visual chart and being very logical about the whole process.

Part of me hates the subtleties and evasiveness of it all, I don't like myself for doing it in a way, but I'm not a confrontational sort of person so I have found that by setting an example of behaving the way I do and living up to my precepts he does follow me very much. It does seem such a small thing but writing it all down seems to take away his anxiety. Since having my own pension, I would just say have your own money and your own bank account and don't let him get his hands on it.

I think that is words of wisdom, you need your own financial independence.

I never thought I'd have to say that. We shared the account at the beginning of our marriage and I could see that my money worried him desperately and I couldn't think why, so I let it ride and let it ride until I found I was being pinched in so badly that I realised that if any money came my way.....

I'd like to move on to another concept, what I call God-mode, and in God-mode they are this omnipotent person who knows everything and you can't argue with them. Some don't but it is sufficiently common to get this "I'm always right" approach and being totally inflexible and omnipotent person - it comes from computer games where you would

normally get shot and you can type in "God-mode" and nothing will affect you and you are perfect throughout the whole game.

Was it Michael Caine had the expression "Not many people know that" and this is what my husband does. He says something, comes out with some weird fact, and he's really cocky that you don't know, it's not something you could be generally expected to know, but he's really cocky that you don't know, and yet when you expect him to know something that he should know, that is generally or universally understood, he gets really cross that you expect him to know. He says "How should I know?" or "What can I do about it?"

My husband says "That's supposed to be common knowledge I suppose".

And it is. Within Asperger's syndrome, we know that the person has difficulty reading the cues, the difficulty is that sometimes when somebody is making some ambiguous or neutral comment, or in the past it was being one of their black characters, somebody they didn't like, they develop almost a paranoia about people, paranoia in the sense that they assume they're attributing malicious intent - "but he was just looking at you", or "it was just a throwaway remark", or "it was not significant" - but no, it's taken on as almost a sense of paranoia. What do you do in that situation?

I don't know - you get punished for several days don't you - and then it blows over until the next time. I think it's important if there are children about you do attempt to say that not everyone's like that - if it's one group of people, like my husband has this thing about the Masonic Lodge and everyone who is in anyway involved is totally evil, and I say my next-door-neighbour is one and is very nice, and I do think it's important if there are children around that you put up a defence.

In a way it's like not having any grey areas - it's always black and white and if somebody's in the black camp, then whatever they do must always be bad and this is a problem they have at school in particular, but also later on as adults in work, is that somebody will make a comment and that person will misperceive it as far worse than it actually was, people are ganging up on me or things like that, and so you get a sense of almost paranoia that's occurring, it's not psychotic, but they do seem to be misinterpreting neutral cues and so you have to explain afterwards that it wasn't intended that way.

You try to bring up your children to think "If you're not quite sure how somebody means something, take it the nice way", but they tend to do exactly the opposite, if you're not quite sure how somebody means it, it must have been nasty, you can't get through to them to maybe look at it the other way.

You know I said about the toolbox, what we would do is, if somebody made a comment that we think may be nasty, we'll either check it out or do what I call a rescue or safety phrase, "Are you joking, do you really mean that, why would you say that", so what we do is we clarify it, we find out, we just check but here the person makes the assumption and that's it,

whereas we would check the reality of what's going on, we would repair or check that situation.

Can I tell you a very funny story that happened when we were on holiday in Teneriffe. We'd been there for about four or five days. One day we were sitting on the first floor balcony having a drink (I was covered with a sarong and D had shorts on) and a car pulled up outside and we never thought anything about it (it was facing slightly to go - you know what I mean - the front pointing out) and I never really looked and then saw a movement in the car and thought this guy had a puppy on his lap - needless to say he didn't have a puppy on his lap and he was doing something - you know - I was reading a book actually - so I said D look down there and wondered whether he should go down and ask for the car to move away and I said "why don't you do something" and he said "Well he's doing it for your benefit - have you got any knickers on?" as if I'd been cavorting and making this guy do this - and all I was doing was sitting there reading a book. He always blamed me for anything that happened - it was me. I had made this happen. Ludicrous.

The assumption is, again in the black and white, is that if anything goes wrong then whoever has been wrong in the past, it must be them, again it's no grey areas of what can occur, so it causes major problems.

Interrupting drives him absolutely bonkers and we had a scenario where I interrupted my daughter and he really told me off, this was at the family dinner table, and I decided to take him on and say look this is ridiculous, this is between my daughter and myself and she's not worried about being interrupted, you know we were just talking, and I did decide to talk about it then, because I felt it was very important, particularly for the older children, that they didn't see me being put down for normal behaviour with them. I tend not to be confrontational but something like that I thought I was role-modelling normal behaviour and that they had got to see that this is normal.

This is where I keep going back to the other kids in the family - they need to learn how to relate to people in an ordinary way, otherwise they're only seeing an unusual interaction going on.

Again on the black and white, sometimes I've noticed that the adult with Asperger's syndrome may have a favourite child, one that they're very keen on and the others are very - there's unequal love for the kids.

Or they can change from one to the other, they can have a favourite and then swap to the other one so that the dis-favoured child then doesn't know what's the matter and why they're out of favour.

My daughter has some of her father's characteristics, a bit clumsy, but very academic, so he identified more with her than with my son who's outspoken and dynamic, completely the opposite, and I think R knew that, that she was loved more and I was always going round saying "Dad does love you but he's not very good at expressing his feelings".

When I talk to some of the brothers and sisters with a father with Asperger's syndrome, there is often a feeling that they were never shown proper love and affection, which really made a major impact on their life, to their childhood.

I think the age of the child as well, because things can often just go along until the child hits adolescence, and that's when it's just like fireworks because then they do start to answer back and also they start their own relationships. My husband got very jealous of any boy that the girls would ever be interested in. He was insanely jealous really. And it wasn't a normal jealousy, it was other people coming into the house and the changes that it brought along.

My third daughter is not actually the favourite child but the one that gets picked on - since she was tiny, my husband has I think very sensitive hearing and she was an incredibly noisy baby, she had a scream that could be heard miles away, and from then she has always seemed to be the one out of favour. It got so bad that when she was doing her A levels, her older sister had got a flat, she went to live with her sister for the final year of her A levels because it was getting to her work, because everything she did was wrong, he'd find any normal thing wrong, she really had a hard time, and in the end I said could she come and live with you for the final year, otherwise she's not going to do very well because he's at her all the time and he never let up.

And not picking up the signals of going too far, where other people would know time to back off.

I have a few other things here - there's one I call the Frank Sinatra syndrome - My Way - it all has to be done their way. Being very critical of others. Lack of affection or emotional support for the children. Intolerant of noise and mess. Hoarding items and sometimes fundamental religious or political beliefs that the person can have.

Social Life

In social life having to do a lot of social scripting and repairing of situations - so in other words explaining to the person if someone's coming round, don't talk about their recent bereavement because their husband died of cancer, so don't say you must be greatly relieved he's finally dead, don't tell the joke about the priest and the prostitute because she's catholic, all those sorts of things, but you also have to go through repairing when they've offended other people, probably like a fire brigade going to all these fires that this person has lit and dowsing the flames - how have you dealt with that?

We had a shop and my husband offended a customer, an old lady, and I knew she was upset and I went out of the shop and I explained to her that he hadn't meant to upset her, and apologised to her and she was very reluctant to accept my apology, because it was my husband who had offended her but I did manage to placate her but it was very difficult.

I had someone who said they would never invite my husband back because he was just so boorish and rude. He just wouldn't speak to other people, it was a very terse yes or no, he just sat there, he just put a blight on the whole party. We never went back there again.

It does mean I am afraid quite often that social life does diminish and people have to realise that in their relationship you either shrink or you have your separate life.

We talk about how we behave before we go out now, what is expected. If it's a professional function I would have to talk to him about how he was expected to behave, and what did he think he ought to do, and it came down to such basics as he would be expected to respond when I introduced him, and he would be expected to talk, and he would actually think of things he could talk about, and that was very difficult. But we had to go through such small things that was expected from him. There was no structure.

It's a rehearsal basically, before you go on stage - these are your lines, this is what's going to happen. What you do with young kids when they go to a birthday party, it's when they're an adult they go to an adult party, because if you're not careful they're going to upset the host by making provocative statements or sometimes behaving in a very adolescent way. Sometimes the person has told the same joke to the same group of people, but people are too polite to say every time we meet you tell us the same joke. They've got no memory for it and keep repeating in the same situation and sometimes their behaviour is very adolescent in many ways. You think that really they ought to grow up.

My husband is two different people in that sense. Providing he's in his own home he can be the life and soul of the party. But take him out of the house to other situations, that he cannot cope with, head down, etc. But in his own home he's an absolute delight, and I have to accept that now of course.

Mine is the same depending on whether he already knows the company, like his relatives.

My husband's the opposite, charm itself and will make a speech in a big room full of business people, or the Rotarians or whatever, and he will enjoy it, but when he comes home he'll go in his study and not emerge for 2 hours and not discuss the evening or the people or anything, it seems as though once he's home he's done it and I expect he's exhausted.

I think that's the point, exhaustion, because many with Asperger's syndrome have to do a lot of intellectual effort to read the signals, some of them have learned the script so fluently that they know how to be the centre of attention and how to do those sorts of things, but the stress of it is enormous and so when they get back home, it is an exhaustion. It's the same with the kids, when they've been at school, and they can end up as what I call a Dr Jeckyll and Mr Hyde, if they are in some social situations they camouflage it, they're OK- but it's like a compressed spring - it gets tighter and tighter until eventually it just unfolds.

Intimacy

I'm now going to go to the topic of intimacy, because in relationships this is going to be important and that is the issue of romance, seduction and foreplay, which does rely on understanding the emotional needs of the other person, and one of the things that can occur is not only a lack of empathy and concern for the emotions of the other but it may be a tactile sensitivity for that individual, so they don't like certain forms of touch and the frequency and value of intimacy in maintaining the relationship, so any particular issues that you face there?

I told C once, and I was joking pretty seriously, that I was starting a star chart and that if you get ten stars you can have sex - he said you must be joking, and I was, but he really thought that I was going to award them.

Trouble is how would he know whether you were joking or not, and other people would know from the glint in your eye or the absurdity of what you were saying, that it obviously must be a joke, but often the person is not picking that up. It's just that there can be issues of the romance, seduction and foreplay, where the person doesn't really recognise those sort of aspects of a relationship.

I would say our sex life has gone out of the window because it always seems to be me that has to start it - he doesn't like to be touched, he doesn't like to kiss, he doesn't like closeness, but he does like sex.

Yes, as a physical release but not romance, foreplay,

Sex is sex - he doesn't have any inhibitions about it - if somebody turned around and said you can have me, he would go with them and come back to me and tell me that he had made love to somebody - it wouldn't be making love, it would be sex, the act, so it gets to the stage where I think well you make the first move, I'm sick of this, but he won't. You would have to make such clear signals, he can't read you and realise that you're in the mood, so now awful as it is, I have to go in and virtually say right come on then we'll do it now - why can't he come to me and say that now and again - it's taken all these years because I didn't know about him for 10 or 12 of them and they do make an effort when you go out with them, once you're together then they start getting, not lazy, but they just stop trying, it's a big effort for him to try, he can manage it for about a week and he can be very loving, but it's such a big effort that it takes . . .

There are certain things that need to be done to maintain the relationship. One of those is to say that you love that person and that isn't said often because that person says well why would you need me to keep saying that, have you forgotten it.

I'm here aren't I?

You have to say well look people still need reminding of that, there still needs to be gestures of affection, romance, those sorts of things, and the person seems to think well the marriage certificate makes it for life, that's it, I don't have to make any more effort at maintaining the quality of the relationship.

Tell me, it doesn't seem to matter what it is whether it's DIY, or driving, or map reading or money or whatever, it's always one extreme or the other, and on the FAAAS website there have been a lot of letters about sexual relationships and an awful lot of women have said that after the wedding their husband has lost interest, and their sex life is practically nil, it's a very common thing. But it's not always so, there are extremes, there are some who have a very active interest in sex all the time.

Yes an interest in sex, not necessarily relationships. In some ways it is an extreme of male characteristics - I think what it means is that the person doesn't know how to maintain the relationship. When we are working on friendships, they may have great problems getting a friend but then they don't know how to maintain a friend - it's the same with a relationship, once they've got that wedding over, the assumption is that they have no idea how to work on that relationship. Their partner will tolerate the situation and they then have no motivation to change what they are doing, to look at the other person, the other person stoically accepts it as life without recognising that in fact that person needs to learn how to maintain the relationship.

My partner has quite a lot of problems in this area, not only tactile sensitivity but if she's not expecting to be touched she will jump and can't be touched, and a lot of funny things like - I need to see where you are - if you're standing behind me I don't know what you're going to do - I need to see you. Partly because as a teenager she was probably close to being abused by trusting men she shouldn't have trusted but didn't understand why she was passive in the situation and they carried on when she didn't want them to. Yes and not giving the signals. Not giving the signals and not being able to read the signals. That leads to quite a lot of problems because sometimes she'll say well I don't want to start anything because I don't know where it is going to end up. But also being very wooden in the process. Feeling that she can't control it, or predict it, so it's because I don't want to end up in intercourse I don't want you to touch me at all.

Not all touch is going to lead to intercourse, to sex, and there are other forms of touch which are to maintain the relationship.

You're forced sometimes to back off from your husbands because I think if you do get tactile they assume you want sex - I've tended to back right away now because he won't just settle for affection, he reads that as a sign you want more.

You haven't been clear of where you intend it to end - and the assumption may be that it's going to go further than that.

Then there is also the sulk if you stop half way..... Oh, totally.

Or they only show affection when they want sex. Yes.

I think that is a risk - yes. *They don't want to know you after, no such thing as a cuddle.* It's not something that the person sees the value of and why would you waste your time doing that when there are far more interesting things to do - it's almost as though their pleasures come in other ways, it's intellectual orgasms really.

I thought my husband was homosexual, because the marriage sort of ended so quickly. I lived with that for a very long time and puzzled and puzzled about it, I wondered if it was part of the Asperger's syndrome - I mean do they have the same sexual.....

I think what we tend to view is the dichotomy of heterosexuality and homosexuality, and I would say there was also someone who was asexual and for quite a few with Asperger's syndrome they're not interested in an intimate relationship with anyone, male, female, or whatever. They're not interested in intimate relationships, it's intellectual relationships but not intimate relationships with anyone, so sometimes because they may not respond to a female the assumption is that they must be interested in males, when in fact they're not interested in anyone in an intimate relationship.

I think mine was interested in anyone who was bright and startling and wanted him, male or female. He's not at all hidebound by conventions.

I think you've got different codes of conduct here. I think it's just that we would normally have certain barriers and here the person with Asperger's syndrome may not recognise those barriers and they look at a relationship for different reasons. If it is a homosexual relationship would not necessarily see that as any way would change peoples perceptions of them or would have all sorts of connotations etc.

I came to the conclusion that he had no idea that anything he did of that nature would have any affect on me at all. That must have been devastating. It does take some coping with.

My husband doesn't ever want to share a bed. We have separate rooms now, separate beds, when we had a big double bed and we had an electric blanket on for both sides, but he only put his side on to make sure I didn't come in bed because its cold. When we've, I'll call it made love, when we've finished, I'm told to get out, that's the finish, you can go to your own room now. It's physical, yes.

I was wondering if anyone else has experienced this, my husband can be very loving and he can be very romantic, (calls of no, no) only after years of training, but he doesn't like being held or cuddled in bed for very long, and when we go to bed I like to cuddle up and go off to sleep and it's driving me insane. It starts off quite happy and then suddenly his breathing starts to become quite rapid and I think what's the matter you're not running a race ... he says oh no I'm not but he is, and imperceptibly he starts to stiffen, it drives me insane, I can't relax, he's all right for about 4 or 5 minutes, then he obviously can't go into total relaxation. In the morning he's fine when he is relaxed and he loves cuddling then,

when he's relaxed after a night's sleep. But it's this preliminary when it all starts off so nicely and I can feel the rigidity creeping in, and I made him go to the doctor, our GP's probably never heard of Asperger's syndrome, and his legs twitch a little bit and she thought he had got twitchy leg problems.

One of the things that occurs in both autism and Asperger's syndrome is an abhorrence of a lack of freedom of movement, it's being restrained, in fact the worst punishment for kids with autism is not smacking, it's not electric shocks or anything like that, it's restriction of freedom of movement, they want to be like birds with complete freedom and they hate being restrained. *Oh, so that's what it is!* It would be a most abhorrent experience, not to have that freedom of movement, it's almost viewed as a punishment. It's not viewed as a pleasant experience, it's like a punishment, something that they have learned to tolerate because that's what you want but don't see any personal satisfaction, in fact the opposite, of a restriction of freedom.

Haven't I read of someone with Asperger's syndrome who actually devised something that could hold them tightly?

That's Temple Grandin - that was a squeeze machine that she's in control of - to give her deep pressure - but not a person. I know Temple very well, she is a lady who has chosen not to have any relationships with anybody.

At one time when C was asleep if I touched him in the night he'd jump, but since he went on to Tamazepam I can touch him at night now and he doesn't do all that moving about.

It's a measure of touch sensitivity, it's restriction of freedom of movement, it's not understanding the value of it.

Is there a history of people having problems with sleep? My husband has to have an excess of heat, no ventilation at all, even in the summer he has duvets and blankets, not a crack of light, we actually had blinds put up and then we had to have double lined curtains all put up at the windows.

Terribly particular about conditions of quiet.

In other words, get the person to relax, it's almost like a hyper-reaction to any sensory stimuli like a touch or light coming in or a dog barking a mile away, it's almost as though immediately, but also with kids in particular, when they awake that's it, they're awake and they can't get back to sleep quite often. So it seems almost an extra sensitivity to sensory stimuli so that when falling off, anything that disrupts their light sensitivity, touch sensitivity, all those sensory systems, and that's it.

Is this general?

No, my husband is the extreme opposite, he can sleep anytime, any place, anywhere, on the edge of a fence.

My husband can sleep anytime, we went to friends to visit and he would sleep.

I've heard of that before, going out to parties and he falls asleep.

I think one of the things is and again I don't know whether it's an issue of a constitutional predisposition to mood disorder, or whether because of the complexities of life, especially socially in the relationships, the person is reacting with strong emotions. But quite often medication does help such individuals, but it's usually medication that's designed to reduce anxiety or depression rather than anti-psychotic medication. So sometimes the SSRI, selective serotonin reuptake inhibitors, that type of drug, may assist the person, in basically tolerating things that previously would agitate them in a number of ways. It may be something that helps lift the mood but we would also look at what things are upsetting them in their life as well, so it's often not just taking the tablets will solve those problems, but quite a few with Asperger's syndrome have relied on low doses of medication, not so much to deal with acute anxiety disorder or severe depression, but just a low level to keep them going in a number of ways, so it's a low maintenance dose sometimes. Did you say C was using medication?

Yes.

I give my grandson 5HTP from the Health Food Shop (which is a precursor of Serotonin) and it definitely helps his anxiety levels.

Can I ask about nightmares? Shouting, screaming nightmares every night, and crying out for help and all sorts of things every night. Has anybody else had the same experience with nightmares? Yes. Yes. You have? Has there been any pattern to the nightmares at all? Well we don't share the same bedroom, but there's shouting and screaming and like a child and I can hear it through the wall - it just goes on every single night. Anybody else?

Night sweats and he can't breathe and a couple of times we've phoned the doctor. He struggles to breath and my daughter also has nightmares.

Night terrors can occur in autism. Kids with autism are notorious for sleep problems and night terrors is something they can have, and we look at a whole variety of things that may be happening there, including certain types of seizures. But, no, that's interesting. Has anything helped in that situation?

He's learnt how to control his breathing now, slow breathing.

I used to go into the bedroom but it gave him such a fright and such a shock that I thought it was wiser not to go in, and to allow the voice to get weaker and weaker and calm and then there is silence, so that's what I do now, I don't go in. Just let it take its course.

Emotion Management

One of the problems can be mood swings where the person can have ups and downs, what I call a Ferrari without brakes, and we have a toolbox or a mechanism of brakes but you can find that the emotions are quite volatile. Sometimes they're confused with bipolar disorder or actually are associated with bipolar disorder, but shall we say it's within the day rather than the longer cyclical nature, you may find some mood alterations almost like a very young baby who goes from laughter and happiness to absolute despair and then moving to something else. One of those can be sudden intense rage over trivia where sometimes it's a minor thing that other people would think inconsequential etc, but here this person has a sudden explosion and it doesn't matter who they're with or what the situation is, it's totally abhorrent and they go over the top and can become quite explosive over minor things. Again you have experience of those?

Story about white socks and not black socks, and he went mad, he said it ruined his day.

It's almost as though the thought is trapped on that topic and they can't get it out of their minds and there's this huge storm of explosion. You think what's the point, it's just socks, who cares? But it's a huge explosion.

Talking about another thing, I was thinking if I could get my husband to smile and look at this life for good, and have a little song or anything that shows emotion, he's so completely level level level that you want to scream and say come on show some feeling, some emotion about something.

But also the person can be very uncomfortable when others show emotional arousal. Sometimes when other people are very happy, the person becomes upset; when other people are very angry, they get agitated, it's almost as though they want everyone to have a flat affect in a way and the difficulty is that when other people are in that mood the person may be unable to cope. Or sometimes then they have a lack of brakes on both the negative emotions, in other words they may be very sad, or very angry, very anxious, but also in times when they should be very happy they can cope for a while and then they get very silly and it's almost as though they can only cope with a mild level of happiness, but delirious happiness that everything's gone right they just don't seem able to cope with, it's almost as though they have this very narrow way of functioning within that emotional variability.

It's made an enormous difference since he's been on the medication after the suicide attempt. I was trying to get him to basically enjoy life a bit more by suggesting ways of having time out, away from the family or going on long walks like he used to enjoy - but he got totally flat, nothing, and that actually produced the feeling that he felt I was pushing him away, which was what brought on the suicide attempt, it totally backfired. Since he's been on the medication and it's only been a few months, he has been like a completely different person, it was as though layers of onion were peeled away and you can see the real person underneath - because it's as if that overgrowth has been getting worse and worse for nearly 20 years so I'm sure there's a kind of chemical reaction which liberates

somebody from this frame of mind because I know exactly what you describe, there was nothing I could do, only this drug has been able to release him.

You have to get them to accept that medication's an option and get somebody to wisely prescribe.

One thing I'd like to say is it might be a mistake to think that person is not content just because they are not behaving as you would.

I think there is an issue we call emotional dyskinesia, or a mask-like face, which we perceive as a sad face, when in fact it's not portraying sadness because we expect greater animation in our faces and when you observe some of the kids with Asperger's syndrome, they look quite sad but they're not necessarily internally feeling that - we may perceive that the person is sad that the person is not showing our overt signs of happiness, so we assume that if you're not overtly happy, you must be sad, when that person may be quite content.

I think that's what causes a lot of problems. Certainly it's caused a lot of problems in our house because C goes around and I wouldn't say he looks sad, he looks cross.

Again it's using a scale that they can relate to in identifying that. It's just that sometimes, we have to remember that the person is different and so what from our point of view would look miserable, for that person may be just contentment but we perceive it as sad, and that's where you need some guidance, I call it an emotional thermometer, that the person goes through to indicate that. But one of the things on emotions is that some with Asperger's syndrome, especially the males in their late teenage years or early twenties, can have problems with alcohol consumption, with binge drinking and using it as a self-administered anti-depressant.

A lot of my patients have abused alcohol.

When he was in the Navy, he joined at 15 and came out at 21, and he spent 6 months in the Navy's alcoholic clinic. He drinks but he hasn't got a problem he's not an alcoholic. But he drank himself silly then he'd go into this clinic, and then back he'd go into the bar, and it's help yourself you've got two days have what you want, and then after that they couldn't have a drink, and they were allowed to go out for weekends.

My husband decided when he was about 16 he couldn't afford to drink and smoke so he stopped smoking, just like that. No withdrawal symptoms. That's one of the positive things about having Asperger's syndrome - perhaps we could find out what it is that lets them stop smoking just like that so we can copy it for other people. When he goes on a diet, he just stops eating. When he thought our relationship was over for him that was it, he cut me out of his life as though we had never been together.

Talking about mood swings - when H leaves the kitchen to visit the bathroom and comes back again in a different mood - it happens within seconds. It's also about this crying

every day. Of sitting with the head in the hands and shaking of the head and the no, no, no aspect and tears just welling out of him like a tap. This can go on for a little while and then right, that's that over. Then he goes onto something else.

And he is having problems with sleep, nightmares, I think you need to talk to someone medically about that. It's difficult to know what's going on but he almost has this huge deluge of emotion coming out which is like a huge tap that switches on and off very quickly that may need to be investigated.

We only find out last year that H had Asperger's syndrome, and he went to see his GP who said I know nothing about it, so if we go and see his GP about these particular difficulties he will say I know nothing about Asperger's syndrome. Where do we go, what do we do, this is the thing.

Discussion about the availability of any experts in autism who could help.

I'd get that investigated because if he's got such horrendous emotions coming out, it must be most unpleasant for him.

[E saying she may be able to help with a name to contact and Tony saying the other alternative may be to use the internet and post a message on the Asperger's syndrome message board describing the symptoms to see if anyone else is suffering the same as you and what worked for them]

You said you were going to say something about lying.

Issues

Yes, that's my next topic. Usually, with the person with Asperger's syndrome when they are very young, they are breathtakingly honest, so when you ask them if they did something they say yes. Later on they tend to notice those who did something wrong. When the teacher says did you do it and they say no and get away with it, they think that's a good idea, I'll give it a try, but when they do, they're very immature because they don't realise that the teacher's going to find out five minutes later or it's a very childlike lie. The issue can occur later on for some, in lying as a quick fix, because they don't know how to repair the situation, they don't want an emotional blow-up, they can't think beyond the next five seconds, so when you say have you taken the rubbish out "Yes" - when they'll know that within five minutes you're going to find out that it's not been taken out. It's not that they're watching the soccer or something like that, it really is a question of sometimes lying, in a way it's almost a poker face, you can't tell, where with others, if you know that person well you can tell they're lying, and this can be quite upsetting, not the fact that they haven't put the rubbish out, but they actually lied about it. Do you have issues with lies?

I don't any more. Do you want to explain why not? He doesn't get sex if he lies. I found out about some lies that had very serious results. We sat in the car and I said I've found

out that you've lied, this is it, if you lie to me once more, then it's divorce. Do you want a divorce? No. Right, well if you lie once more, I don't care whether it's a big lie or a small lie, it's a divorce. What is going to happen if you lie to me? You will divorce me. I went through this several times - it's like talking to a child - and he hasn't lied since - not that I found out - until last week, when I found out that he'd bought quite a large item and I said how long ago did you buy this and he said ages ago and I said what did I say about lying and he said "Three weeks". I just laid it clearly on the line. This is what will happen. It has to be something that really matters to you before you make a threat - I had to be certain myself it was such a big issue and it was one of those things where I felt I'm not going to have it any more.

If it affects them, they can curb their behaviour? Yes. Is that a harsh statement?

I'm afraid it is, it's being very mercenary. It's more or less saying if you do this, this is what's going to happen to you, in other words don't do it to please me, do it because your life is going to be easier. *I thought that was just my husband, but it's very common?* It's very common with Asperger's syndrome. They've got to see it from their perspective. If you say this is going to happen, which will affect them, then they can sometimes consciously stop themselves doing it. It's not going to be 100% but you've just got to do it. How does it affect you personally, not how it affects you as a partner. *You've got to be totally implacable to do that!* You've got to be trustworthy when you say that, you've got to mean it, if you deviate you've lost credibility, it's almost marriage by contract.

Do we know, how does it affect people long term - finding out you've basically married a child? You've married a robot!

I think it's a major cause of depression. It makes a major readjustment - as I'll come to as one of the last things here.

A lot of women's own health is very bad, many have got fatal illnesses, all sorts, at the very least she lives on the edge of a nervous breakdown.

I find a lot of women blame their depression on Asperger's syndrome, many get readmitted to mental hospitals.

Why do these people get married in the first place, if they don't want any emotion?

I was diagnosed with cancer 5 years ago and when I went for my treatment, my trouble was, one doctor actually turned round to me and said the reason that I'd got it was pressure in my marriage, and that didn't help me at all, because I was coping with the illness and I was also being told it was his fault and I didn't need that at that time, and nobody would undertake to give me help in dealing with it and that was a real nightmare.

If you look at all the major causes of depression, they all occur with somebody with a partner with Asperger syndrome, controlling life, all those sorts of things. You could

almost say, depression can be a normal reaction to having a partner with Asperger syndrome. *It's really hard when you're told your illness is a result of something you can't do anything about.* Yes, which is going to make you more depressed! *The upheaval and the enormous thing you have to go through at the same time, of something potentially fatal, perhaps your death, that really got me angry.* I think one of the major issues is depression, and the issue of should I go or should I stay is a major problem - and what strategies strengthen the relationship is certainly support from other partners, and I think one of the advantages of today is to meet others for a sense of validation of the issues that you're going through and the common ground. On the other topics that we've had, there have always been exceptions, but there are certain common grounds where at least you know you're not alone.

What tends to happen though at the moment is that support is given to a family where the child has Asperger's syndrome, the mother then goes to the Asperger Support Group to support the kids at schools and so on, but actually they're supporting each other in the relationships, so when they have the coffee mornings and the husbands aren't there, then it's often the husbands who are the major topic of conversation, so not necessarily the school, the kids and the therapists, etc., so often it's done on an unofficial basis by the support groups, but really there needs to be things like the Newsletter you've got, internet groups, etc., but also support from other family members and ones children, that is the kids who may not have Asperger's syndrome, because at least you've had some validation there that they're OK and you live vicariously through your kids in a way. It's also having an independent social life. What's interesting is that often when the partner says I want to go to the pictures and I'm going with a man friend, the partner says oh fine.

It's also going through relationship counselling, of the right sort, and I think that's the key issue, finding the right counsellor.

In a previous comment you said something about ageing, could you fill in?

It's just that in most people in the later years of life, your inhibitions dissolve. It's just that in old age, the person can previously have held it together as a conscious effort but in old age may not be able to do so. We are also suggesting that for some with Asperger's syndrome there may be a higher incidence of Alzheimer's in this population, and in fact if you talk to the experts in Alzheimer's and you talk of what we know of the broader autism phenotype or the Asperger personality, quite a few people with Alzheimer's had before the Alzheimer's developed, almost the Asperger personality type, so we do find a higher incidence, the research has yet to confirm this, but a potentially higher incidence of Alzheimer-type features.

Question here from A about AS type personality

We don't know, but certainly when you then start looking in a family history, those individuals that had the Asperger traits, and as they died, as you go through your great uncle

and so on, then I picked up clinically signs of Alzheimer's, and in some families that has been an issue.

That's what you're saying, signs of, you're not talking about it's that you have, we are talking about external expression, I'm saying maybe that's not the same thing.

Yes, it needs to be further investigated, but it does mean that there may be a deterioration in skills and a reversion to all sorts of childlike and more autistic like behaviours, that suggest that that partner may have difficulty in all conscience in maintaining or staying with the relationship, because the kids have grown up and "Right, I can go, but now he's ill", and "do I go now?".

I don't know whether you are saying that, people here are going to think "now he's going to get Alzheimer's!"

This is not a foregone conclusion - it's just that we're only now exploring the ageing process - we've done a lot of work on the kids and in their age range, the older ones we were never quite sure whether they did or didn't, and now there's a certain population where we have more information and so we are looking at the ageing process and looking at the statistical predisposition to certain illnesses, and seeing within the autistic spectrum whether certain illnesses are more common. One that I suspect that may be more common, just from clinical experience, not from research yet, is Alzheimer-type deterioration.

When you say its Alzheimer-type, I was just thinking about ages ago when - my father's a lot older than my mother - and the geriatrician who saw him said that frequently elderly people were diagnosed as senile, when in fact they were getting more and more depressed, because it's a pretty awful time of life if you're losing your physical faculties.

One of the differential diagnoses is between depression and Alzheimer's and there are tests now you can use to distinguish those, but it's something that as a couple they need to be aware of, that the person may have certain medical needs as they age, which leads to the decision regarding the relationship, it may be that it goes on.

Where would you go for counselling where you could be assured that people would understand and you wouldn't be in a position where you would be trying to explain what the problem was and what its consequences could be.

Venetia - In terms of trying to get some advice, some of my patients may want to have tests, want more in-depth analysis of what's the matter with them, and the National Autistic Society gave me some names of people in my area for diagnosis.

I've found that some who call themselves experts in diagnosis do not have the knowledge and experience necessary to be able to diagnose AS.

You can call the Derby Relate telephone line on a Tuesday.

I just wanted to make an observation from my own family, which links with the question of some of the characteristics merging into the effects of ageing. In the case of my father-in-law and his son, there was memory loss of the sort that you expect with ageing, but it related particularly to facial recognition. If you are the kind of person who didn't have much eye contact, who didn't focus on faces anyway, it's quite likely that as your memory begins to fail, it would be in those particular areas that it goes.

In the ageing process, I think that as everyone ages there may be a change in characteristics and abilities and we're only just exploring that within the Asperger's syndrome population, but it may be that they have previously, say from 40 to 70, been able to cope reasonably well but after a certain time they may not be able to cope as well, and then who is the only person who can look after them, it may be their partner.

Even in the preliminary stages, I was thinking of steps taken by my ex-husband to leave his university job where it was increasingly embarrassing that he failed to recognise his colleagues, and actually became a computer consultant where he would meet people just for a particular task. So he didn't have to have a memory, because you only meet them just on the one occasion! A very constructive way of doing that! Yes, and very lucrative.

Good! I think on that positive note it's time to end.

Today has been so informative and rewarding - thank you so much Tony and Venetia.

It's really just passing on information that I've picked up on this. What I hope you do is then plant a few seeds in your own local areas. It's just that I find that partners are actually my heroes in what they're doing, and I think they need understanding and support in what they have achieved with their partners. I take a great delight in doing workshops like this because I like meeting the people who are at these workshops!

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Many thanks to Edith, Maxine, Susan, Sylvia and Brenda for helping to organise the day. Some of the audience's comments and questions were not picked up on the tape recorder.

Useful websites:        [www.tonyattwood.com](http://www.tonyattwood.com)  
                              [www.faaas.org](http://www.faaas.org) (Families of Adults Afflicted with AS)  
Relate helpline:        01332 345678 every Tuesday 10.30 am to 4.30 pm  
                              Counsellors specially trained in Asperger's syndrome.

*Asperger's Syndrome* Dr Tony Attwood, Jessica Kingsley Publishers 1998  
*Shadow Syndromes* John J Ratey and Catherine Johnson, Bantam Press 1997

Distributed by:  
Asperger Backup Campaign  
15 Walpole Road Bournemouth BH1 4HB

*Patron: Dr Tony Attwood*  
01202 399208

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Last Saved By: David Potter  
Total Editing Time: 924 Minutes  
Last Printed On: 25 July 2000 15:24  
As of Last Complete Printing  
Number of Pages: 50  
Number of Words: 21,962 (approx.)  
Number of Characters: 125,187 (approx.)