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Women's Hour, BBC Radio 4, January 3rd, 2002

Now, Asperger's Syndrome used to be known as "the trainspotters' disease". It's a condition which is related to autism and 2002 has been designated as Autism Awareness Year to highlight the kind of problems it can cause. The symptoms of Asperger's are usually not so severe. It does, though, cause obsessive behaviour and difficulties with communication. People who suffer from Asperger's Syndrome are usually male and they generally can't understand the feelings of the people around them. They don't know, for instance, if the people around them are happy or upset and they take everything that's said literally. The partners of people with Asperger's often don't know that bizarre and cold behaviour patterns can be put down to a known syndrome.

Claudia Hammond reports.

Claudia Hammond - Tom and Emma Rigby live in Oxfordshire with their daughter, Katie. Tom always felt that he wasn't like everybody else and never really felt the need to make friends.

Tom Rigby - I knew I was different from about the age of ten or eleven. I didn't seem to think like other people. I was a bit of a loner. I didn't make friends very easily. I didn't feel the need to make friends. My parents found me quite difficult but they thought I was just an obnoxious teenager. And there was no-one really to help me until I met Emma.

Emma Rigby - When we started living together then I realised the big mood swings of depression to the lethargy, the obsessive-compulsive disorders....manic moods as well, particularly at odd times of the day, maybe at midnight, wanting to tidy and clean and organise, perhaps the kitchen cupboards.

TR - I'm absolutely amazed that our marriage lasted because I was never outwardly horrible to her but it was almost like having a difficult child. It was very difficult for her.

ER - Yes, it was. And it was the not-knowing, when I came in from work, what the situation was going to be like. It did used to worry me. Basically, I thought he was awkward and difficult, lazy and obnoxious. (laughs) It does make him sound dreadful but that wasn't all of the time, just some of the time. But when it happens, it really happens. When the rudeness happens, it's shocking.

CH - Eventually Tom was diagnosed with Asperger's Syndrome. It's a type of autism which can difficulties with communication and understanding. Suddenly, it all made sense.

TR - It was one of the best moments of our lives, I think. Emma burst into tears. I nearly did. It was a huge relief.

CH - Sometimes the diagnosis comes too late and a relationship has already ended. Brenda Wall and her husband split-up in 1988. Eight years later he was diagnosed with Asperger's.

Brenda Wall - You read all of the advice books and all the womens' magazine columns and everything and you try to follow all the advice they give you and they weren't any use. People with Asperger's say it's like coming from another planet. You're talking to someone who has a completely different understanding or view of what a relationship is. Sometimes something happens that you really need to know about, which is very important and they don't tell you. So you say, "Why didn't you tell me?" and he says, "I thought you knew". And it causes endless muddle and chaos and confusion.

CH - Long before diagnosis Brenda had noticed that her husband seemed to interpret things differently from her.

BW - They misunderstand what you're saying. And they accuse you of the most awful things. I mean, I now know that our behaviour baffles and bewilders them just as much as their's baffles and bewilders us.

TR - I mean, I go to social situations and I tend not to, much to Emma's dismay sometimes, hide my feelings: I really don't want to be there. And people will come up to me and make small-talk and I'm really non-interested in what they have to say. And, whereas most people would smile politely, I will look the other way and show that I'm really not interested. Which some people find very rude but people who get to know me just know that that's the way I am.

CH - But is it difficult for you if you're with someone who can't read emotions very well?

ER - I've learnt over time to control my emotions. There is absolutely no point in bursting into tears for effect because he can't understand what I'm feeling at the time. So the best way to deal with it when I have an emotional problem is to sit down and discuss it practically.

CH - How is it different from people just behaving inconsiderately?

BW - If somebody is selfish or they miss something and it's caused inconvenience or something to somebody else, sometimes they will see it

themselves and they'll be sorry. Or if it's pointed out to them, they can see it and they express remorse but with this they never see, they never see that they've done anything. They're astonished that anybody's upset or offended by what they've done and they think that if you are offended or upset, it's your own fault.

CH - There's no cure for Asperger's but Cognitive Therapy and medication like anti-depressants can make it easier to manage.

ER - Once we got the diagnosis we knew we had to change our life completely. So now we realise the need to plan everything and we have certain routines for things. Tom doesn't really go shopping anymore because we recognise that that's a really high-stress situation. There's lots of other things like general tasks around the house. He's not so good with cooking because he can get "tunnel-visioned" on one thing. He may notice that the tins in the cupboard aren't the right way round while he's perhaps got some soup on the cooker. And also looking after our daughter. We've realised now that because he finds it difficult to understand other people's emotions that he can't really meet the needs of a young child.

CH - But Brenda Wall feels that a diagnosis alone won't just make everything better.

BW - It's a double-edged sword for anybody who gets the realisation that their partner has Asperger's Syndrome because, on the one hand you're extremely relieved, you are not going mad, you are not going insane, it is not your fault. But then you've got the knowledge that you are never going to have the relationship you wanted.

CH - There are strategies that couples can use to make life together a bit easier. Maxine Aston, author of *The Other Half of Asperger's*, is a Relate counsellor specializing in Asperger's.

Maxine Aston - It's very important that the partner without Asperger's Syndrome is very clear, very precise and very direct. The person with Asperger's will not be able to understand double-meanings, will not be able to understand sarcasm, will sometimes take things very literally and it's important that the person without AS says what they mean and means what they say.

ER - If it's something small in my own mind, I know that it's going to blow over in time, so I'll automatically go and put right whatever has gone wrong and just wait for it to pass. With an anger, with a rage, it exhausts Tom, so he will go and sleep or rest. There have been some major crises which have gone on for much longer and that just takes time. It takes a lot of talking, it takes a lot of working out. Life is pretty much turned upside-down.

TR - When Emma was pregnant with Katie, she was eight months pregnant and we'd just moved into the house and it got to the stage where I just could not cope with anything. And I got very, very down. My family were out in Turkey so I just got on the next plane to Turkey. Most people would say, "My God, how callous, how ridiculous", but it actually did me a lot of good because I went for a week and I came back and I was fine.

CH - So do you find yourself changing your behaviour much so that you don't get him annoyed?

ER - Totally. Even in a conversation, if there's been a problem and Tom has done something to upset me, what I have to do is set the conversation up, that it's - "I have a problem with what has happened. I want to sort this out." So it's very much to do with me, reducing the blame on him.

CH - So you're more likely to get what you want if you approach it that way?

ER - Yes, yes. As opposed to going, "It's your fault, your problem....".

TR - You just accept that I'm always right and you're always wrong! (laughs)
Then life will go on tickety-boo. That's how I look at it.

ER - I put very little value on winning. If I've stopped an anger, a crisis going on by agreeing, by going along with it, then I've won, haven't I?

TR - I play to win in everything I do. I don't like coming second.

ER - Tom doesn't play cricket anymore. (laughs)

TR - I've run out of villages to play for.

CH - Maxine's experience from counselling couples is that even though only one partner has Asperger's, you've got to have give-and-take all round.

MA - If the partner without Asperger's Syndrome feels that they're the only one doing the changing, they're the only one working at this, it'll be unlikely that it will be able to hold together and the person with Asperger's Syndrome, as long as he or she is aware of what they're doing and the effect it's having, then he or she is very capable of making some change. Not huge changes but small changes, maybe just controlling a particular obsession. Each person with Asperger's is unique. They don't all do the same things.; They don't all make lists, they don't all clock-watch, they don't all have an idiosyncratic hobby. They are all uniquely affected.

CH - So what's in it for the partners, having to stick to routines, deal with bad tempers, explain everything carefully, along with loving someone who can't read your emotions. It doesn't sound like much fun.

MA - There's plenty of love there but it will be shown, often, in a very different way to what women would probably expect from a man without Asperger's Syndrome. I've known people with Asperger's go to great lengths to actually show their partner how they do love them and it might be because he knows that she likes a particular restaurant and he'll arrange to take her there but it's unlikely that he'll sit there and come out with all the verbal, emotional loving, making her feel special.

CH - And Emma knows that there are benefits.

ER - The commitment is great. I know that Tom's always going to be there. He likes to have the secure, stable relationship. He's a very, very hard worker and is very keen to support the family that way but there's a lot of love involved there. He's obviously superb at cleaning cupboards! (laughs) We have very clean cupboards, which helps a relationship. But, no, the love and the commitment and the need to talk....you know, he needs to talk about everything in a lot of detail, is very positive in a relationship because we talk everything through.

MA - I am convinced that it can work and some of the marriages I looked at were sort of ranging between twenty-five to thirty years. Well, I think that's quite amazing.

TR - Yes, I am 150% committed to this relationship and I think that's why it's proved so strong between us.

ER - If there was a cure for Asperger's, between us we've decided that we wouldn't take it because Asperger's has made Tom into a very special person. He might be a very dull and boring person without it.

Aspergers in Love: Couple Relationships and Family Affairs

Maxine Aston

Foreword by Gisela and Chris Slater-Walker

Jessica Kingsley Publications (www.jkp.com)

2003 224pp

ISBN 1 84310 115 7

pb £14.95

Asperger Syndrome (AS) has often been considered to be incompatible with love and relationships, but as the number of people who are diagnosed with the disorder increases, it is becoming apparent that people with AS can and do have

full and intimate relationships. Comparing and contrasting both AS and non-AS partners' viewpoints, this book frankly examines the fundamental aspects of relationships that are often complicated by the disorder. Drawing on her extensive research and established career as a Relationship counsellor, Maxine Aston has produced a much-needed analysis of intimate relationships where one adult has AS and this book is a must for all those with AS and their partners, as well as for friends, family and counsellors.

An Asperger Marriage

Gisela and Christopher Slater-Walker

Foreword by Tony Attwood

Jessica Kingsley Publications

2002 160pp

ISBN 1 84310 017 7

pb £12.95

"[When] one partner has Asperger Syndrome, making the diagnosis can be problematic. That is why reading Chris and Gisela's book was so fascinating and helpful....They do not pretend that it is easy, but their factual information with some poignant yet amusing anecdotes make this an enjoyable, as well as informative, book to read. I would highly recommend the book for couples where one partner has Asperger Syndrome and for professionals, not only those working in this field, but anyone who works with people with relationship difficulties. It is definitely on my list of recommended reading"

Extract from review in *Communication*, magazine of the National Autistic Society.

Chris and Gisela met while both studying Russian at Manchester University. They have been partners for sixteen years. In 1997 Chris was diagnosed with Asperger Syndrome. For Chris, this was an explanation of why he has always regarded himself as "socially handicapped". For Gisela, it meant coming to terms with a marriage in which there would never be an intuitive understanding despite Chris's good intentions. For the couple it was the beginning of a long and still unfinished process of learning to live with a disability regarded by some as incompatible with marriage.

Chris and Gisela married in 1994. They live in Hertfordshire with three children from Gisela's previous marriage and their son, George.