

The desperate diagnosis

For many diagnosed with Asperger Syndrome as adults, it comes as a relief to know why life has been such a struggle. By **Donna Fleming**.

Scott Graydon knows what it's like to be a square peg in a round hole.

All his life, he's tried hard to fit in, to be like everyone else, but most of the time he's failed.

Scott finds it difficult to know what to say or do in social situations. At school he was shunned and teased, and in some jobs he's had he's been bullied. He has problems learning new things and multi-tasking, and when things don't go according to plan, he becomes very anxious and finds it hard to cope.

"I've always tried to put my best foot forward," says Scott, a polite and smartly-dressed 43-year-old who has an unusual, very formal way of speaking but is nonetheless articulate. But so often, all he's ended up doing is putting his foot in it.

For most of his life Scott has wondered why he has struggled to do things that seemed to come naturally to others, like following instructions or making friends.

Now he knows. Four years ago he was diagnosed with Asperger Syndrome, a form of high-functioning autism.

Although it was first described by Austrian paediatrician Hans Asperger back in 1944, it took 50 years for it to become standardised as a diagnosis.

These days more and more children are being diagnosed with Asperger's thanks to doctors becoming more aware of it, but there are lots of adults with it who slipped through the cracks when they were young and don't know they have the disorder.

"Society seems to think of Aspergers as a childhood thing that people magically grow out of, but they don't," says Natasha Delgarno, adult liaison officer for Autism New Zealand's Auckland branch. "There are a lot of adults affected by it to different degrees. I get at least a couple of new cases every week."

Often these are people who've gone through life being labelled as quirky eccentrics at best, and weird freaks at worst. Asperger's can cause different levels of impairment, and some people may have typical 'Aspie' traits like social awkwardness and an obsessive interest in a favourite topic but can lead a 'normal' life, getting married, having a family, and holding down a good job.

Often their intense interest in a particular subject can lead to a career specialising in a field like IT or engineering. Aspies can do well jobs that require technical expertise but not a lot of social interaction.

And although they tend to be socially awkward, some people with Asperger's have successful relationships. Their partners may overlook traits like repetitive behaviour and speaking bluntly because they have other endearing qualities.

However, there are many who can be much more disabled by Asperger's. Some find it so hard to interact with other people that friendships, let alone romances, are out of the question. They may also be unable to hold down a job – if they get past the interview stage – because they become overwhelmed by the workload, or are perceived as rude, difficult or even weird by co-workers, says Natasha. Workplace bullying can be a major problem for Aspies.

"That's why I recommend people with Asperger's who are having ongoing employment difficulties should disclose to employers that they have it. Hopefully employers will be more understanding."

But unfortunately Aspies can't always explain to other people why they behave the way they do because they don't understand it themselves. They and their families know they're different, but they don't realise it's due to a developmental disorder.

This was the case with Scott Graydon. His late father, a teacher, wondered if Scott had autism because as a small child he displayed behaviour like rocking, but doctors dismissed it. "We didn't know then there was such a big range when it came to autism, and you could have Asperger's," says Scott's mother Audrey.



Scott and Audrey Graydon

PHOTO: TED BAGHURST

After many years of getting nowhere with doctors and psychologists, she became convinced Scott had Asperger's after hearing a man talk on the radio about his experience with the disorder. "He described it as like being a train. Taxis can go anywhere but trains have to stay on their track. As long as he was running on his tracks he was OK – if he came off everything derailed. That's Scott – if things don't go according to plan he can get very upset."

Scott's inability to read people and tell if they're joking or serious was always a concern, as was the fact that he sees everything as black and white and takes what people say literally. His high anxiety levels were also troubling, says Audrey.

"As a parent you worry. You worry about how they are going to cope when you are not there. I worry about jobs. He's applied for hundreds of jobs and never got them – even things like pushing a laundry cart in a hotel. And some of the jobs he has had have been very difficult for him, and he's ended up working with some nasty people."

"It's a shame. Scott is such an interesting and happy person. He's so helpful. He has so much potential and it's upsetting that he hasn't been able to achieve it. Having Asperger's is also so isolating, and it's sad to think of life with no friends."

But being diagnosed four years ago has improved life for Scott, who lives with his mum. He now attends a social group run by Autism New Zealand and mixes with other Aspies.

The diagnosis has allowed him to go on an invalid's benefit so there's not so much pressure to find a job. He'd like to work, but in the meantime he can devote more time to his abiding passion in life – study of the Bible and religions. He talks with great enthusiasm and obvious intelligence about his interest and how he's planning this year to do lots of in-depth reading on subjects like universalism and Calvinism.

He has other interests as well – he's a talented artist, a good cook and does martial arts.

Scott's diagnosis has also led to a referral to a psychologist, who he sees fortnightly for help with life skills like making conversation. He was recently anxious about the impending visit of a relative from overseas but

his sessions with the psychologist helped him prepare conversation topics and even practice what he would say.

A diagnosis can not only open doors to professional help and agencies like Workbridge (an employment service for people with disabilities) but it can mean a change in the way Aspies view themselves, says Natasha Delgarno.

"For some people it can be quite frightening to get the diagnosis – although they know they are different they can't bear the thought of having the label of a disability."

"But a lot of people are often hugely relieved. They think, 'At last I know I'm not a freak, I'm not mistakenly on the wrong planet.'"

And once they know about Asperger's, they can learn ways of dealing with situations. "You can learn certain skills," says Natasha. "It's never too late. It's not easy and you need support, but there is always hope."

Scott agrees with that. For 39 years his life was a disaster, he says, but finding out Asperger's is the reason he's had to struggle was the best thing that has ever happened to him.

"It feels like a giant mountain of oppressive weight is no longer on me."

NATASHA'S ADVICE TO ASPIES

You have to create a life that suits you. Work out what you need to be happy and healthy. For example, if socialising is stressful for you, work out how long you can manage and arrange a time limit on visits. Learn what your limits are when it comes to working – don't work fulltime if you aren't up to it.

Don't compare yourself to others. Realise that you have a disability, but you can work with it. Be kind to yourself and accept who you are.