

# Our Stories



Surrey Autism  
Partnership Board

## Introducing the people

The best people to help others understand the needs of people with an Autism Spectrum Condition (ASC) are people who have an ASC.

The three stories in this factsheet are real people's stories. Their names have been changed and they've chosen a different photo to represent them.



*Rebecca*

Rebecca was diagnosed with Asperger Syndrome when she was 21.



*Daniel*

Daniel's mum tells his story. He was diagnosed with an ASC when very young.



*Jonathan*

Jonathan was diagnosed with Asperger Syndrome when he was 5.

# Rebecca's Story

## *When I was little, people thought I was badly behaved*

I found it hard to make friends and I hated school because I got bullied by other pupils and by the teachers.

It wasn't until I was 21 that I found out I had Asperger Syndrome.



### Having a diagnosis has helped me.

Being diagnosed meant that my family and other people in my life understand me a bit better and can help with the things I find difficult.

## *Having Asperger Syndrome affects me in lots of ways*

Work, home life, independence, family and friends are all affected.

### Here are some of the things that don't help:

- Going hysterical.
- I need to have a routine.
- Talking too much, talking too loudly and too fast.
- It is hard for me to make my own decisions.
- I have trouble understanding money and difficult letters.

## *The most noticeable thing about me is that I talk too much, too loudly and too fast*

Luckily I have found a job where this is ok, but it can annoy people.

I can't see when people are bored or fed up with me talking to them and this has made it hard to find and keep friends. The friends that I do have are good ones.

Some of them are from different countries in the world and I made them when I was younger and moved to different countries with my family for my dad's job. Moving around the world when I was a child has helped me get used to changes.

### I can't help getting hysterical and I don't like it.

This can happen whenever I'm upset, on my own, worried about something or if I have to make my own decisions.

I try to relax by listening to music, watching TV, colouring, reading a good book, meditating, doing reiki or going on my swing in the garden.

I have also made a stress bag full of relaxing things, but none of these work when I'm really upset.

None of them work when I am really hysterical.

## *I like to read and recite poetry*

Apart from this being relaxing, it's also a special talent. If a poem interests me I'll remember it and be able to recite it from memory, even if it is 10 minutes long. This impresses the people at work and people I talk to about Aspergers.

### *I need to have routine in my life.*

Sometimes it's hard for me to change my routines.

For example I wash up alphabetically and by colour.

If I want to work, I have to plan what I'm doing, and have time to go over what I've been asked to do.

There are some days when I get too upset and agitated and cannot get to work.

Work has improved my confidence and I feel like I am gaining some independence.

### *I do lots of voluntary work in my spare time.*

I especially like working with children.

I was home schooled when I became a teenager and I still prefer to learn like this.

I recently got my NVQ 2 in Childcare but now I'll have to get a NVQ 3 to be able to get paid for my job.

This is frustrating because I know the children I help at the nursery like having me there, but I'm not sure I'd be able to complete a level 3.

It is hard for me to change my routine, to fit in with work.

## *I attend an Asperger Syndrome group once or twice a month*

I can meet and talk to other people who have Asperger Syndrome at the group. The good thing about this is that we can share stories, ideas and helpful information about living with Asperger Syndrome.

The bad thing is that we mostly don't get on with each other because none of us can really understand how our actions make other people feel. We are like magnets that don't attract.

### *My goal is to one day get my own home, cook my own meals and pay my own bills.*

My worry about living on my own is that I will be alone most of the time because I find it hard to make friends and when I am on my own I worry and then become hysterical. If I do this in a flat it will be a problem.

With people around who understand what makes me anxious, they can help me to make my own decisions, these can't be rushed. I am feeling more confident in my own abilities now though.

## *I'm not sure what the future holds for me!*

I'm still hoping I'll win the lottery so that I can buy a big mansion and have servants to do all the chores.

In the meantime I'm working on being a great employee for my boss, trying to be on time for work and always use my diary for appointments.

# Daniel's Story



*I am mum to Daniel a 25 year old gorgeous pre-verbal young man*

Daniel is severely autistic, has a severe learning disability and behaviour that challenges.

**Daniel was diagnosed unofficially by our GP at 11 months.**

The GP then struck us off his list as he didn't want to deal with us! Official diagnosis took another year.

*Early intervention can make a huge difference for people*

Having a label not only gave me a reason and an understanding for Daniel's behaviour but also gave us access to services.

**As Daniel grew his self-injury increased.**

Both the school and local respite home struggled.

The local Challenging Behaviour team and social services got involved. Both were brilliant.

Daniel continued to struggle so we were the first family in Surrey to get Direct Payments for their child.

This meant I could employ someone to come out with Daniel and I making life a bit easier as he could run fast!

Then we were the first to get tri-funding for an out of county placement as I felt strongly Daniel needed and deserved more specialist input because of the severity of his self-injury.

**We had Portage and music therapy at the local hospital.**

Daniel then went onto the local Severe Learning Disability School and had respite at a local home.

I also worked hard with Daniel, one of the things I remember was my taking him out shopping a lot, just for one thing, which we built up on.

We cleared many a shop!

*I learnt that behaviour which challenges is a form of communication*

Daniel bangs his head on hard surfaces, especially when anxious. For example if he saw a dog not on a lead or someone on a mobile phone, things that were out of his control.

As Daniel grew up I became better at reading and understanding him and avoiding self-injury escalating most of the time! He loves music, long train rides and Disney DVD's.

## *Daniel never has spoken with his voice*

It's one of the many things people ask me about. He speaks to me with his whole body, how he stands or rocks, flaps or squeaks! He points with his eyes.

When you get to know him he is very expressive. And if Daniel looks deep into your eyes it's as if he is touching your soul.

### **Childhood was a rollercoaster.**

Lows and many incredible highs. Communication, anxiety and sensory issues were the main areas we all helped Daniel with.

A strong Person Centred Plan. Structure, repetition, lots of exercise (long walks are good!) a sensory diet, health checks and downtime being key.

With lots of understanding, therapies, reasonable adjustments, patience and love Daniel flourished and grew to 6 foot! Not sure how, as a vegetable has never passed his lips!

**As a mother, Daniel's self-injury has been the hardest thing to emotionally cope with.**

Over the years I found ways of helping my own anxiety as I needed to stay strong for him.

At present I am having reflexology sessions which are paid for with carers direct payments. They are fab!

### **My views on autism have evolved over the years.**

I now see beyond the label. Autism is just another human difference, just as valid.

Autistic people should not be disabled by society and out of date stereotypes, myths and prejudice.

## *Transition to adulthood meant I could move Daniel back near home*

The difference between the education system and the adult world are huge. It's been like falling off a cliff.

Expectations and attitudes are so different. Training of staff is so different. There is no continuation of everything that Daniel was brought up with. So with the support of the local Learning Disability Teams and Intensive Interaction we are having to start again with Daniel.

### **My hopes for the future are better transitions.**

- For there to be less of a gap between child and adulthood services. To have better training and to raise the profile of staff.
- For there to be increased use of Positive Behaviour Support with behaviour that challenges with proactive not reactive working.
- For there to be a shift in attitude of autism and acceptance of autism as a culture and not something to be pitied, feared or cured.
- For there to be less jargon and more use of ordinary language to bridge the gap of 'them and us', rather than promoting and reinforcing it.
- For people to embrace neurodiversity and work together more.

*And that Daniel lives a fulfilling ordinary life, just like everybody else*

# Jonathan's Story



*My diagnosis of Asperger Syndrome was made at a very young age, when I was five I believe.*

My autism has given me positives and negatives in my personality.

## The positives

It gives me a very good attention to facts and written information given to me.

I am outstanding with numbers for example. I think I am more passionate than an average neurotypical about my interests.

I have a very logical brain as well, academically I have done very well and I believe my neuro disadvantage has helped me with that.

## *I'm less rigid about my routines*

I don't eat the same food constantly and actually find repetition boring now.

Due to my repetition problems fading, I feel my written communication and verbal skills have improved too, especially after going to university.

## The negatives

It gave me a considerable list of weaknesses, but through a substantial level of input and therapy I have now largely overcome these problems.

I can talk to and socialise with others quite well. I still sometimes find it hard, particularly when I meet lots of new people I don't know, like at a big party or gathering.

Particularly if it is with people with no interests in common with me at all.

I really try hard to socialise and fit in as I hate being different. Sometimes, especially at school, I found it tough.

I used to be very obsessive and possessive but now I have overcome those things.

## I feel the best way to tackle your fears and weaknesses is to face them.

For example when I turned 18 I went to many house parties and even clubbing and it has built me some confidence.

A big problem has been anxiety and dealing with high pressure social situations. Again I find it challenging sometimes but again I am trying to face the enemy using the social skills I have.

At university, I feared I would not get a 2.1 due to being on the borderline grade-wise for most of my degree and I always thought about the consequences if I did not attain that in terms of job prospects and postgraduate study. I achieved that in the end which is something I will always be proud of.

## *At present I don't need any intensive help regarding my condition*

I would like to acknowledge Assist at the National Autistic Society for the fantastic support and advice they have given me over the past few years.

## *The anxiety problem is a work in progress*

I am hoping I will suffer less anxiety than I do in future as I feel one of my larger weaknesses is being scared of failure.

I do sometimes interrupt conversations when I shouldn't as I can find it hard to sense the right moment to speak in a group. This is something I want to analyse. I want to learn to be patient and wait until it is my turn to talk. The biggest thing I have drastically improved is adapting to change and not getting too angry and getting on with it. In reality that is all you can do.

### **I don't take any medication or have any counselling to help with my anxiety.**

It is something I deal with by just getting on with things. If I keep myself occupied then it keeps my mind off of my worries.

When it does get on top of me I discuss it with close connected people to me, or I even mention it to my consultant at Assist.

### **I have a range of hobbies & interests**

I am a big football and darts fan which I like to play.

I also have a strong interest in travel, listening to music, going to gigs, going to the pub with some friends and seeing and visiting places with my girlfriend.

Certainly quite a broad range of interests. I would say I am quite outgoing, but I also like my time to myself as well.

## *I am aware that people on the autistic spectrum hate noise and have other sensory differences to neurotypicals*

The only one I have is a sensitivity to food texture. I hate mushy food in particular such as cooked vegetables. I eat the majority of them raw as they have a crunchier feel to them. Also not cooking them saves water and energy, and keeps more of the goodness inside that is lost by boiling them!

### **When I left University I initially found it difficult to find a graduate job.**

I found this very stressful. I had to do temporary work for a while. It took me 15 months to find a permanent job. I now work in digital marketing where my analytical skills are serving me well.

## *I have aspirations to go travelling for a few months and teach English as a foreign language to children from a poorer background*

It is something I want to do in the future, and I feel it would improve my people skills. I'm looking at Thailand as a possible destination.

My childhood dream jobs were a train driver (as I have been passionate about trains for my whole life), an air traffic controller and a transport planner (improving roads, railway links and other public transport).

I want to continue to develop my career and I am open to anything that's related to my degree and that I may have the skills to do. Maybe if teaching abroad goes well I will consider a career in that area.

# Useful websites

[www.autism.org.uk](http://www.autism.org.uk)

- The website of the National Autistic Society.

[www.nassurreybranch.org](http://www.nassurreybranch.org)

- The website of the National Autistic Society Surrey branch.

[www.surreypb.org.uk/Autism.html](http://www.surreypb.org.uk/Autism.html)

- The website of the Surrey Autism Partnership Board.



There are seven factsheets in our series about Autism Spectrum Conditions.

You can download our factsheets from [www.surreypb.org.uk](http://www.surreypb.org.uk)

This is the website of the Surrey Autism Partnership Board



1. Autism Spectrum Conditions (ASC) - An Introduction
2. Diagnosis
3. Communication
4. Useful strategies for life
5. Social care and community life
6. Health services and support
7. Our stories - three stories from people with ASC

## Credits

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