the girl with the curly hair

Asperger's and Me

Alis Rowe
“An overwhelming desire to be away from my peers...”

I wasn’t really sure how to begin - or even structure - this book. The thing about my Asperger’s Syndrome is that it can’t really be broken down into different sections. AS is my identity and way of living. I can’t just split it up into sections because all the sections would end up overlapping. I think my Asperger’s Syndrome looks a bit like this:

This is my “wrong planet.” It is a tangled web of all the things that make up my Asperger’s Syndrome, including anxiety, depression, OCD, ADHD, hypersensitivity, emotional sensitivity, giftedness, individuality, etc.

I’m going to start by writing about some experiences at school, because they’re probably some of my earliest, most tangible memories of really standing out amongst everybody else.

Nursery and infant school were not too bad, although my mum says I used to run out of school because I did not want to stay. Teachers always tried to get me to play in groups of girls instead of with my best male friend.
At primary school, the teachers used to say to me, “Why don’t you go and play with the girls, Alis?” But I always only wanted to play with my best friend, who was a boy. He and I were inseparable for many years and are still in touch now.

I think that if you have AS and get on well with one particular person, you should be encouraged to be with them. Friendships are important because we find them so hard.

I’ll always remember this one time, I asked the teacher for a ‘Desk Move’ because I wanted to sit somewhere different. We had the Desk Move (where you get to move your place in class so you can choose who you want to sit next to), and I ended up on a table with five of the naughtiest boys in the class! The teacher said to me, “Alis, don’t you dare ask me if you can move ever again”. I guess she was disappointed with where I’d ended up sitting?

I really hated secondary school. I was bullied for being so quiet. What a strange reason? I’m still traumatised by the mockery of my peers and even some of the teachers. Some of the things I remember people saying are:

- Why are you so quiet?
- Why don’t you talk?
- Why don’t you like us?
- Do you talk?
- What’s wrong?
- Smile!

Some of the children used to jump out at me and shout “speak!” as though I was their pet dog.

I suppose it was the combination of being quiet and socially awkward that made me an easy target for bullying. Honestly, I really did just have nothing to say most of the time. Small talk had never come naturally and I struggled to follow the conversations.
What exactly is the “normal mask?”

It’s quite a common thing amongst those of us with Asperger’s Syndrome, to put on a “normal mask” whenever we have to face the world. Girls especially, tend to be highly capable of appearing “normal” and that’s why we’re so often undiagnosed. The normal mask represents an “autistic person in hiding.”

Over time and through different experiences, I have learned how to be social. I have ‘high-functioning Asperger’s Syndrome,’ which to me means I am more able to compensate for my communication and social difficulties through logic and reasoning. As someone with Asperger’s Syndrome, I am fortunate to be fairly adept at communicating and being social. I don’t think you would initially think I was on the autistic spectrum if you talked to me for the first, second or third time. It’s sad that for many females, we’ve perfected our masks so well, that by the time we’re eventually diagnosed, a lot of people don’t even believe us (more about this at the end of the book).

When I think about my bouts of depression I notice that they are almost always triggered by some kind of social interaction. My depression is probably brought on by my endless acts of conforming - just trying to be normal and act “normally” around others My normal mask looks a bit like this:
As a parent, don't nag your child to be “like the other kids.” It will make them feel extremely upset. Accept them for who they really are! “Neurotypical” is not equal to “good.”

I have to socialise every day, to varying degrees. It doesn't matter how much or how little socialising I do - before, after and preferably in between I have to have breaks to rebuild. I get fatigued having to wear the normal mask. As soon as I step outside of my house, the mask goes on and with it comes a continual anxiety that's like a little worried dog sitting on my shoulder.

I love my family because they see, live with and wholly accept the special person beneath my mask. They understand my need to retreat or close off from the world; it's just never questioned. I don't have to ever explain myself, it's very uplifting. Unfortunately though, my family also get to see the worn out, anxious, depressed, unhappy side of me. It's only at home I can be this way, due to the disguise of the normal mask. I wonder if relationships with the closest people are in some ways the hardest ones? I've always been most happy being at home - I feel safe and almost touch a beautiful state of “enlightenment.”

It gets better as you get older. I am now a lot more self-aware and know my limits. I accept that I can have fun socialising, I just need more time to rest up afterwards.

Although I am an introvert and my hobbies are solitary, I love being with my family who accept me for who I am. They don't push me into talking or attending social events because they know my personality, my limits and my boundaries. Staying close to my family - who know everything about me, my idiosyncrasies, quirks and love me unconditionally - combined with staying away from other people, makes me happiest day to day because I feel that I function at a depth that most people do not. I love being with my family but, at the same time, I love being alone. I really enjoy it when everyone is at home, but we're all doing our own individual things. My dad and I share our computer space. We sit on the same desk but at opposite ends. I can sense he is there but it's totally okay not to interact all the time.
An AS in shutdown may appear cold, distant or insensitive, but honestly this isn’t the case - we’re just trying to recuperate from a situation that has been stressful for us. Don’t feel offended.

My own shutdowns can be caused by anything. It could be a result of something someone has said, watching something distressing on T.V., a disruption in my routine, or a combination of things.

The worst shutdowns are the ones that are built up from lots of different things. It doesn’t matter how small or big the scenario is to someone else. It could be anything from as terrible as someone’s death or as simple as a joke I took the wrong way, the event will have the same consequence: shutdown.

Aspies are hypersensitive. This means our brains get overloaded quickly. Shutdowns or meltdowns often occur because we’ve been exposed to too many things or too many people, ultimately causing sensory overload.

Shutdowns can come on either gradually, over a few days or even weeks,
The thought of suicide seems like an escape from a world I never wanted to be in from the start.

Thoughts of suicide and dying are not only horrible burdens in my life, they are frightening; I am afraid of the unknown and the devastation I’d cause my family. Thankfully my suicidal thoughts are indeed just thoughts and I know I could never act on them, no matter how much I wanted to. I am very close to my family and my animals.

I do not want to write any more on this subject. It upsets me.

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When something happens that makes me feel depressed, it can sometimes upset me so much that I’m unable to do the things I usually...
My family have known me my entire life. They have been by my side at the doctor’s. They have brought me out of shutdowns. They have supported me through depression.

Yet, despite being a part of all of these things, they still don’t really know what it’s like being me, having Asperger’s Syndrome.

So I wrote this book.

The hardest thing about having Asperger’s Syndrome is that it can seem like an invisible condition. Females in particular, can be expert at masking their symptoms.

Tomorrow I will get up and leave the house, go into work and get on with things, my challenges totally oblivious to the people around me. The next day will be the same. And the day after.

I hope this book will build the bridge between people with Asperger’s Syndrome and the rest of the world. Most people with Asperger’s Syndrome are able and willing to work and live a “normal” life, with the right support and adjustment. The main problem is that most people are just unaware of how they can help.

So, let us begin our journey into the wearing but wonderful world that is

**ASPERGER’S SYNDROME.**

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**London**