

It's Not Easy Being Me

Stella Hofer is 19 and was diagnosed with Mosaic Down Syndrome (MDS), a lifelong condition at around four years old. Making friends and maintaining relationships isn't easy. Stella shares her thoughts with us.

Stella will be using her creative writing skills to regularly report on news and write articles for Llais.



Mosaic Down Syndrome (MDS), is a rare form of Down Syndrome, and although it isn't entirely the same as the more common form of Down Syndrome, it does still bear similarities, as I share the same number of chromosomes as a person who suffers from Down Syndrome, which is forty seven. It isn't easy to live with MDS, as I do find adults and people older than myself easiest to socialize with, and my friends, who are all

somewhere around my age, are mostly into doing things together, while I prefer my own company and want others to respect my private life.

Interests

I live on a farm in Llanddeusant, where my Mum and I work in our own home café on the way to Llyn Y Fan Fach, a famous walk, where Hollywood hit Wales in order to make the film Stardust, in which a young boy

is on a quest to prove himself. I've always enjoyed cooking, so I bake cakes, serve customers and learn to give them the right change, and sometimes cook my own meals at home. I also love to read, draw colourful pictures, belly dance and travel abroad. I've worked as an assistant in a book shop, my old primary school, a nursery and graduated after six weeks of experience in Lampeter University.

Being Creative

I enjoy writing because I feel really moved by the books I like to read, and I think it's a necessary skill to be creative. Up until now, I've only dreamt up stories of magic and adventure, crime and family fun, which I wrote in the common room in school when I'd seen to homework, or simply wanted to indulge in something other than music from Lily Allen and Lady Gaga. My favourite books have got to be *The Lord of the Rings* and *The Chronicles of Narnia*. I find that by reading books I'm able to connect with characters just like I can with real people, which is what makes them so interesting to me.

I am in my first year at college in Carmarthen on the Pibwrlwyd campus on Mondays, and Jobswell on Wednesdays, where I study the Art Access course in Design and Fine Arts. The practical side of it is a lot of fun, although it is worth using the computer as well. I've produced a good number of paintings and sketches, and have learnt to stand at an easel from arm's length, which helps my posture, how to use a pencil in other ways, and to wear appropriate clothes for classes. I'm not incredibly ambitious, but I know that I want to be an illustrator as I start to picture my stories so much, and since they're set in a second world apart from ours, I've decided that I'll draw a map of it one day. When I leave home

and settle down somewhere in the future, I'll want to have my own studio where I can sit at my desk to sketch and write.

Socialising and Special Needs

From my own experience with relating to my friends despite certain Special Needs, I can see only a small difference and that it is no big deal. Anyone can have a level of Special Needs and anyone can have a problem with socialising. Sometimes it comes easy, other times not so easy. Others may be something like a loner and want to socialize; others may not want to do so. It could be to do with relating to family members or to yourself. If ever one had such a huge problem with socialising it would or would not matter to them. It all depends on the person and the personality.

My experience in this field of relationships is down to how I relate to those in my family. Some of the lack of socialising I blame on myself; some of it I put down to Mum for how she wanted me to be. It is not so easy to let go of a person once they're growing up. The relationships between mother and daughter, father and son and friends are so important.

Growing up

For a child it seems so easy to relate to other children of their own age, yet it can become a bit of an issue later on as you grow

up. Even a couple of Special Needs can't get you down. Just because one may need extra help doesn't mean you can't socialize.

It is also different in coming to terms with yourself and your Special Needs. That is just the same as finding your identity as you grow up. Teenage years are when you begin to appreciate yourself. From what I've experienced it is a very different thing from relating to others. I have been doing my best to my friends rather than to myself as I am a bit of a loner.

Friends

Friends are so valuable. You have to value your friends before yourself if you want to be good at socialising. A difficulty in relating to others is one Special Need that everyone has, and in those with MDS (Mosaic Down Syndrome) and Aspergers Autism it is more pronounced. What with MDS I find it quite hard but my Dad and his girlfriend believe that, aside from me, it is something anyone can have.

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That's why I seek solace with my friends who don't seem to find it so daunting. It's about trying to be accepted and accepting who I am is just as hard, as I'll be living with MDS for the rest of my life. That seems to be my destiny as a very wise friend of mine once said.

At school it's pretty much how I like. Sometimes some children younger than me decide to pick on me but I ignore them. I just go by what I taught myself whenever someone tries it out on me: walk away. It's much easier to block silly insults than it used to be.

Relationships

Occasionally I have been too dependent on certain people

rather than on myself. That created a bridge between me and my friends. My dependence on helpers didn't help and it was also just because they were there that caused it. When I look back on that I think to myself that it was meant to be, so as to give me an insight into what my friends felt about me which would hopefully help me see past my helpers.

I still feel sad about past relationships sometimes. Sometimes I feel bad about some of them. One relationship with a helper almost made us inseparable. That was wrong of me and even though I don't regret it I use it as a stepping stone towards future relationships so that I don't relate to the wrong person next time.

The main thing I'm trying to bring across in this article is how

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socialising can be made harder by pronounced Special Needs, or else what it may be like for someone who does not have a particular syndrome or condition. It doesn't make me feel brave or confident but it shows that things could be better for me.

My own opinion

I'm not asking anyone to agree with what I am trying to say as I have my own opinion and everyone else is entitled to think what they want. I'm not trying to speak for those in the SEN department or to teach anyone a lesson. I just happen to be one of many children that are begging to be heard and appreciated for who we really care. I care about those people who aren't as lucky as me and I've got support from my family.

If I was to have just one friend amongst so many who could actually express what they think and feel I'd be luckier. I feel misunderstood sometimes and I don't have a best friend anymore. I used to but now I feel more alone than ever amongst my friends. I just want to be accepted and be one of them; I don't want to be reminded of what my mother encouraged me to be.

Anyone who understands what it's like to be someone like me please be there to tell me I'm not alone and that I have friends who probably find it just as hard. I just think that people who find it as hard need more than words or a hug to feel really accepted; it takes a number of really good friends to help you and that's all I ask: for my friends to just be there, so I know I can talk to them and I will find it easier to face relationships away from school. I ask only for friends.

Stella Hofer