

Sofia – My Story – MEN2B/3 (2021)

What is your condition?

“I have MEN2B which affects my endocrine system and ganglioneuromatosis.”

What symptoms do you experience?

“So, I have quite big lips and bumps on my eyelids and on my tongue which I got from the MEN2B and from the ganglioneuromatosis.”

What led to you getting diagnosed?

“When I was 10 weeks old, I was diagnosed with my MEN2B and then at 6 months old I was diagnosed with the ganglioneuromatosis.”

Tell me about some of the procedures you’ve had?

“So, when I was younger, I had a thyroidectomy and then when I was 4 years old I had an ace button put in to aid with a medical procedure I used to have to have every day. Recently I had another operation that has now helped to give me a better quality of life so I’ve had quite a few different operations, but they’ve all been to help me have a better life.”

How have the operations improved your quality of life? And how does the MEN affect your life?

“Before my recent operations I never really knew how it affected my life because ever since I can remember I was always having these medical procedures every day but now after my most recent operation I’ve realized that actually it affected me quite a lot. A lot of my night-time routines were having this medical procedure every day but now it’s a lot better because I don’t have to have them as often or they don’t take as long so it’s just helped me a lot because I can now do the things that every teenager wants to do and spend time doing the things, I enjoy instead of having to have medical procedures every night.”

How does your condition make you feel as a teenager?

“So, I’ve always been quite self-conscious because of the MEN2B and so I don’t really go on many sleepovers with many friends. I don’t really go out with my friends that much because I’m quite self-conscious of my lips, and how big they are - I worry about what people think of me all the time but with the medical procedures as well it’s also stopped me from being able to go on sleepovers because it was something that I couldn’t miss it was something that if I did miss I’d get quite ill and it stopped me from being able to go out with my friends that much and go on the sleepovers that everyone else was going on. These medical procedures, operations recently have helped quite a lot with that so I can start going on more sleepovers with my friends and spending more time out of the house after school and it will just be a lot better.”

Has that been difficult over the years not being able to do the things your friends have been doing?

“It has been tricky but also I’ve never really been a person to go out on the streets that much and hang about with my friends, but it has been quite tricky to sometimes have to not go on a sleepover because I’ve had stomach ache or not been able to go out to town with my friends because I’ve had to have this medical procedure and it has been quite tricky.”

How is your condition monitored?*

“So, every six months I have to have a check-up and every three years I have an MRI scan to check everything is still going how it’s supposed to be going.”

And how are things at the moment?

“Everything is really good at the minute. I am having to keep an eye on things at the minute, since my last operation and it has recently controlled my life but after a while it should get back to normal and it should be a lot better.”

Tell me about school and what you enjoy studying?

“I really enjoy studying Spanish and Geography and also DT with the practical part of DT just because I find them really fun to learn about different places and about how to make things.”

How has it been juggling schoolwork and appointments?

“It hasn’t affected me that much at school apart from maybe the odd appointment during the school day, but Mum has always tried to get the appointments after school, so I don’t have to miss any school because it’s something I didn’t like to do because I didn’t like to be behind. For me it’s quite hard to catch up with lessons because of my aching in my muscles so I’ve always wanted it to be after school and most of the time it has been.”

Can you explain about the aching in your hands? And how this affects you?

“So the muscle aches came with the MEN2B and it is quite hard when I’m needing to revise for the exams and generally just in classroom work it’s hard because I always end up being a bit behind in the lesson and it hurts for the rest of the night often. Like, often it hurts for quite a while and it is quite hard for it to always be hurting but I kind of have to get on with it and with the work and have breaks during the lessons and try and get it to stop hurting and then carry on.”

Can you explain what this pain is like and where it hurts?

“The aching is in my hands quite a lot near the muscles of my thumb and it doesn’t go, it’s just one of those pains that is there, and somedays it will be really bad and somedays it will be absolutely fine.”

You told me on the phone that in the past you’ve been teased at school. Tell me what people have said to you and how that has made you feel?

“Often people at school teased me, mostly for my size because of my thyroidectomy. When I was younger it stopped me growing as fast as everyone else so I’ve always been quite small for my age and a lot of people tease me for that, but then also my big lips; a couple of comments about them and it just makes me feel quite upset. Just because I’m different, people still make fun of me for no reason because that’s who I am and there’s nothing I can do to change it but it does hurt you. It is quite upsetting when you know someone’s talking about you and saying that you’re small, or ‘oh there’s no way she’s in year 6’ just because I look younger than I am.”

What have you done to block that out and remain positive?

“I just remind myself that I’ve got some really good friends who will help me get through it when things are hard or people are mean. They’ll stand up for me quite a lot of the time when I don’t want to, and I just remember all the times that I have done something that I’m proud of and the fact that people can’t stop me from doing that. I’ll do what I can do to get the best out of me, and I won’t make myself hide away just because people have been mean to me.”

Tell me what you enjoy doing, and what makes you happy?

“I enjoy drawing quite a lot. I do drawing on my laptop. I do a lot of digital art. I do a lot of roller skating and at this point I’ve only had my skates for a year and I’ve grown so much from practicing and practicing. I spend a lot of time with my family. We play quite a few board games all together, even though my brother’s younger than me, we still play games of us all together. I enjoy playing video games with my brother as well which is quite fun.”

Tell me about your MEN – does it stop you doing anything you’d like to do?

“There isn’t really much that it stops me from doing, apart from in the past so maybe just not being tall enough to go on some rides that I’ve always wanted to go on, not going on sleepovers and going out with my friends as much as everyone else can, but apart from that it’s not really affected me that much.”

Tell me about the support you get from your family?

“So, my family is really supportive of me. When I choose to do something because of my condition, or I say I can’t do something because of it they’re really supportive and it means a lot to me because their support helps me get through it and I think if they weren’t there I would have given up and I would have really struggled to get to the point where I am now and battled through it all when I was younger.”

Do you feel the support you’ve had from your family has helped you at school?

“Yeah, it’s helped a lot with being at school and my family supported me during school and with all the work that I’m having to do and helping me when things are hard.”

Tell me about the support you’ve had from AMEND, and in particular the Young Person’s Group?

“So, I’ve had a lot of support from the Young People’s Group and it’s helped a lot because knowing people are there. Before I knew of AMEND, I never really knew how many people suffered with MEN and it’s helped a lot because they understand how it feels when you’ve got a hospital appointment, or you’re worried about something. They understand what you mean and know how they can help and it’s just nice to talk to people who understand what you’re going through.”

Why did you want to participate in this project?

“I wanted to show awareness because like I said I never knew there were so many people who suffered with it and I think showing awareness, spreading awareness of MEN will be a really good thing and I wanted to be a part of that.”

What do you want to do in the future? What are your hopes and dreams?

“I really want to do something in design and do something that’s going to change, like help people in the world for the better and I want to be able to design something that will make peoples’ lives better.”

Why is it important to be positive?

“It’s important to be positive because if you’re not positive you’re going to think everything in a negative way and even when things do get tough you’ve got to find the positives, otherwise you’re not going to get through it. Ever since I started school and even when people were mean to me, I had to find the positives in what I was doing because otherwise I wouldn’t have got through it and if you’re not positive then you’re going to find yourself not doing as well as you can do because you won’t believe in yourself but that’s all you’ve got to do you’ve got to be positive and believe in yourself as much as you can.”

Based on your experiences what advice would you give to someone watching who may be experiencing difficulties, like you've faced?

“As much as it's hard to block it out and try and carry on because that's what everyone is going to say, you've got to stay positive and carry on doing what you're doing because you're doing well. If you let yourself think about what they're saying all the time and you overthink what they're thinking and what they're saying about you then you're not going to live your life, and it's your life that matters not thinking about what they're thinking all the time and not worrying about what people are saying about you. It's about living your life to the standard that you want to live it at, and you are going to get through it and you've just got to try your best.”

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