

Cameron – My Story – MEN2A (2021)

How old were you when you were diagnosed?

“I was diagnosed at the age of 2 and because of that I don’t really remember a lot about it. Just from what my mum has told me really, I was diagnosed and had my surgery at the age of 3 and yeah, moved on from then.”

What was the surgery you had, and why did you have to have it?

“I had a Prophylactic Thyroidectomy and I had to have it because they diagnosed me with MEN, and it was getting ahead of the curve and taking my thyroid out before it became cancerous and more dangerous for me.”

When did you first become aware of your condition and what it could mean for you?

“Well, I think I only properly started recognizing it when I was getting the odd day off school here and there to go to hospital to go for my appointments and blood tests and that’s really all I’ve noticed that and having to take my medication every morning. Other than that I don’t really see much difference to myself compared to all my friends.”

What was it like for you at school?

“I’ve known nothing else and I think with school, not overly knowing the full impact of everything that it has. A lot of my friends were jealous because I kept on getting 2/3 days off school a year to go up to London and, I only ever told them about the meals and the pick and mix my mum used to get me after the blood tests and that’s sort of all that I really remember about school, other than that I was normal, and just like everyone else and playing football, mucking about and winding up the teachers pretty much.”

Did you speak to your friends about it?

“I don’t really tell people straight away. They normally find out when I have an appointment or something because like, I think it was at college my best mate found out because I was going up to the hospital and he just asked if everything was OK and I just explained to him that I’ve got this genetic disorder that means I have to have a blood test every year and an MRI every two years or something just to make sure I’m healthy but it doesn’t overly impact me much at all really.”

Do you ever worry about what the tests and scans might reveal?

“I think I’m quite unusual in the fact that I don’t overly think about what the scans might, or blood tests could come up with. In my mind it’s just a get it over and done with so I can go and treat myself to lunch because I’ve got a day off work.”

What medication do you take?

“So, I’m just on Levothyroxine at the moment, so it’s literally just two pills I need to take every morning and then crack on with the day pretty much, that’s all I need to worry about.”

Why do you have to take this medication every day?

“It’s pretty much because it replaces the function of my thyroid. All I really understand about it is that if I don’t take for a few days then I feel a bit more tired and grumpy. I just take it, so I’m not too easily wound up at work really.”

What was transition like for you?

“I think the main difficulty for me was really remembering to get on a different train rather than I think there was a few times I sort of went on autopilot to go to the paediatric hospital and I was supposed to be going to the adult one, but I think I’ve been quite lucky with my mum having been at the adult hospital for quite a while before I transitioned so I’d met a fair few of the doctors already and at AMEND events and everything like that so I’d sort of met and got to know people so transition was quite easy for me really.”

How did your MEN affect your planning for travelling?

“It was quite a relatively easily planned travelling in the end. I ended up getting it all sorted with two weeks really. I think the biggest thing was trying to get my 6 months of Levothyroxine to take with me, but I ended up just emailing the doctors surgery saying I need 6 months of medication because I’m going away and not being able to get it and they pretty much responded with just saying, yeah, that’s OK. We don’t have much choice we’re going to have to give you it if you are going away so that was pretty much it. Other than that, it was quite good fun. I found it easier to remember to take my pills whilst travelling than I do when I’m at home and just making sure I always have my medic alert on just in case something happened, but I never really had it in my mind that something could happen.”

Do you think it’s more challenging if you have a condition like MEN?

“I would say once you get round trying to organize, your medication, if you can get your medication sorted out easily, the rest just falls into place you’ve got less to worry about. I think the stress I had was trying to fit in the places I wanted to go to in the length of time I had.”

What is your life like at the moment? Tell me about your job and what you’re looking forward to in the future?

“Well, I think at the moment, work, especially in December is relatively stressful but it’s a lot of fun and I really do enjoy it. It’s not for the faint of heart but, yeah. It’s fun. And as for the future I don’t overly think about it an awful lot. I tend to just go with what happens and all I can think of for the future is, I’m not overly sure if I want a family but that’s not down to MEN or anything, I wouldn’t ever let it hold me back in that aspect and the doctors are very good with asking questions about whether I want kids or anything like that and what my plans for the future are and they’re always offering advice and help which is nice how it’s always there if I need it, if I ever get to that point in time but at the moment I’m very much focused on work and enjoying where I’m working at the moment so that’s all I can think of.”

Tell me what you do for a job and why you love it?

“I’m a chef in a restaurant up in Orpington, the third in charge up there and yeah. It’s a nice sort of brunch and a la carte restaurant doing quite a few covers normally so it’s a very busy environment working with a very close team, especially with the kitchen because you’re working 16/18 hours days, 5/6 days a week sometimes and you’re always together so it’s quite nice.”

What advice would you give anyone who has perhaps been diagnosed, and may be worried about the future?

“I’d definitely say not to worry too much really once you’ve had your surgery or anything like that, you can very much move on and carry on as anyone would bar obviously the hospital appointments occasionally, but you can turn that into a nice day out going to a restaurant or something, but I’d very much say don’t let it go to your head, don’t let it hold you back, it’s nothing too taxing to cope with in my personal opinion anyway and it should give you that mentality of, I’ve got through that so I can get through other things in life as well.”

Why do you think it's important to be positive?

"It's generally, just good to be positive about because it's not, uh, It really doesn't hold you back. It's not the sort of thing that should ever really get into your mind as this is going to stop me from doing this and doing that because at the end of the day if it's something you want to do you can always find a way to push yourself to get to wherever you want to be in life, MEN or not."

How has AMEND supported you?

"It's helped a lot with generally understanding what it is, what I've had and what I could potentially have in the future and it's also very good for meeting other people with the same condition and like this project is doing, letting you hear stories of other people with the condition as well and it just sort of is a good support platform for helping everyone through, there's just so much information to learn from."

What was your biggest challenge?

"I think the biggest fear was probably the blood tests, I didn't overly like needles, but I think the Hospital appointments have got me over that now."

How have you come to deal with this?

"It's very much the more you go through it the easier it is. You eventually don't feel the needle at all anymore, anyway."

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