

Joel – My Story – MEN1 (2021)

When were you diagnosed and what were your symptoms?

“So, I was diagnosed when I was 16. It was a funny actually because I didn’t have any symptoms, it was because of my grandmother. She was diagnosed very late in her life and she was having symptoms and then obviously the way that MEN works is that it goes down the line and me and my sister both got tested at the same time, she’s four years younger than me so yeah, we both got diagnosed at the same time and both just kind of getting on with stuff, no symptoms, nothing and then just yeah, a phone call one day saying you need to go and have this test for this genetic disease so it was a bit out of nowhere really so yeah, thankfully no symptoms but a bit of a blind side in terms of how we were told we need to have a genetic test.”

How did your diagnosis impact your studies?

“So, I was kind of diagnosed around 16 which is just as you start sixth form which wasn’t ideal really. I kind of, I didn’t handle it very well in terms of the diagnosis as well as my A-S Level exams so I failed all of my first year of A-Levels, completely flunked every single exam so I had to then redo them all in my second year of my A-Levels and do them all in one go which wasn’t ideal or the best way to do them, I wouldn’t recommend that but the hospital that I was put under the care of wasn’t particularly handling my care very well so that was kind of an added stressor, and it kind of sounds a bit bonkers in terms of some of the other stuff that I’ve managed to scrape through, but I do consider those years to be so stressful and some of the most stressful two years of my life. I kind of muddled my way through it and then in that second year spent a lot of my time after school really trying to salvage A-Levels and put my diagnosis at the back of my mind which is easier said than done so it was an interesting time of my life I would say and very stressful.”

Tell me about your first year at University

“So, my first year at University was a typical, freshers really, kind of making good use of one pound shot nights which probably in retrospect were just shots of expired floor cleaner that the club had kept, it probably wasn’t even alcohol and then very late nights in halls, with my friends, ordering pizza at 3 in the morning and then getting up for 9am lectures, just becoming nocturnal and sort of experiencing as much of this freshers lifestyle, it was amazing I really enjoyed it. Take anything away from this if you go to Uni, you have to do halls, that’s the only caveat I’d put on it, it’s the typical experience, you can really make it your own, but yeah I really enjoyed my first year. Bit of a baptism of fire in terms of growing up, but it was yeah, very enjoyable.”

How did life change for you in your second year at University?

“So, towards the end of the second semester of my second year, I was diagnosed with cancer, so some of the tumours they’d been keeping an eye on that you normally just grow with MEN and just can be benign for years, which is what happened with my grandma. Between scans they would rapidly grow and spread. At the beginning of the summer, I had to go in and have a Whipple procedure. I won’t even begin to attempt to explain what they did, go google it, it’s very complicated they kind of removed lots of bits and bobs, chopped my pancreas into thirds, so the summer I was meant to be going into the shared house with all the people I’d made these connections with throughout the year, you know we went from halls and that summer between 2nd and 3rd year was meant to be that summer of fun, yeah and living a proper student lifestyle on your own, with your mates so I had to spend it

at home recovering and that wasn't kind of in the plan and also as I left hospital and in the recovery process, which they didn't tell me before I wasn't able to drink anymore so that kind of part of Uni culture sort of abruptly stopped and a few of the friends I had at the time sort of suddenly disappeared and stopped hanging out with me, couldn't comprehend that I wasn't able to drink and it was always met with the ah, but just a little bit, could you just have a little bit of alcohol so I suppose in that sense it was a difficult summer, one that sort of cleared up I guess the friendships that we had and tightened it up in terms of people started to see me because they wanted to see me not just because the first year mindset of drink so yeah, it was a difficult time and sort of changed the trajectory of a lot of things that were to come during my life really."

What impact did your condition have on your overall University experience?

"So, my Uni experience kind of changed from that point really, having a condition like that, flaring up so spectacularly meant that I couldn't go out as much because I was so tired all the time, I wasn't able to do things that my peers were doing, you know staying up until 4/5 in the morning and getting up for the lectures the next day and really just in terms of time management now meant I had a much more finite amount of time to do things because I had to spend so much time resting which at University, the timescale just goes out the window usually and you can play with a lot more of your evenings but that sort of stopped."

How did this impact your future career plans?

"In terms of work I suppose I've always thought of being in your twenties post-University as the time people go out, make mistakes in their career, try and work out other jobs and then kind of find one that sticks and one that you enjoy and that was my plan. I'm quite lucky to live near London and there is a plethora of opportunities there but after the surgery it feels sometimes that I have the energy levels of a geriatric snail so I've had a few jobs that I've had to give up simply because at the end of the working day my body was screaming for rest and that could then be followed by pain attacks that knock me back 2 or 3 days so the sort of career aspirations of just work incredibly hard for like 10/15 years after Uni life and then you're set up for your career I just wasn't able to do. I've not been able to do that, so I've had to adjust those views really."

How have you managed the balance between your condition and your career aspirations?

"A big part of adapting to that I suppose work/condition balance is learning how to be kind to myself in that I do have this condition and I think as a lot of people have found recently that kind of wellbeing, spending time with the people that you love is more important than commuting for 3 or 4 hours a day and I think that's especially important if you've got a condition as well because often the normal, everyday stresses that people can take into their stride often exacerbate conditions and their symptoms so I've readjusted what I look for in a job so even though a lot of my peers are absolutely smashing it in terms of going in and forging their career which I can be jealous of sometimes, I've tried to kind of think ok, I need to be at home more so I'll look for jobs that are home based. I can't be doing 12 hours a day because the condition will flare up its just a necessity that over the years I've come to terms with and incorporated."

How have you learnt to do that?

"It's definitely been tricky in terms of trying to weigh it towards wellbeing. Practically I think I've really tried to push freelance things, so whenever I look at a job now it's always how long would the commute be, or can I work from home, is it something that I can do and enjoy that maybe will stress me out less, yeah it might pay a bit more but probably isn't something that I want to do. I think in terms of adjusting to get to that point where you're kind of accepting that you've got the condition and it does have an impact I think I've done a lot of counselling and therapy to work on accepting that new life that I've got and that actually looking after your wellbeing doesn't necessarily mean you have to sacrifice that part

of your life and being grateful for the fact that you are relatively well and that I've got people around me that I love and rather than wishing that things were different that I want to go into London and I want to pursue these things that I can't do and that's sad but OK, that's the cards that I've been dealt and being happy with the life I have now rather than something that is over there and I can't change."

How are you at the moment?

"I'm doing alright at the moment, again I'm trying to forge a career path where I have the best of all the worlds which is staying at home as much as possible, seeing all the people that I love and doing something that I enjoy whilst earning lots but who isn't trying to that and again things come at one expense but in terms of my condition I'm quite stable at the moment, I had to have surgery last year in the midst of the pandemic which was interesting. It wasn't the usual, I say usual, I've now got three surgeries under my belt so I feel like I've got a good understanding of what a normal surgery looks like so it's interesting but all the tests have come back from that positively so I'm not worrying about that and just trying to start my career off really trying to kick off what I want to do for my career which is difficult but I'm in a place now where I feel ready so it's exciting."

What do you do to keep motivated & positive?

"It can be tricky sometimes to keep the motivation there. I've got a lot of active, healthy friends who are really smashing it in all aspects of their life and it can be difficult not to compare yourself to them but I've again really tried hard to focus on me and be appreciative of the life I have now and the comparison is the death of happiness, so really try and make time for things I enjoy and surrounding myself with the people I'm really close to that really sets me on my way and re-energises me and during the summer I spend most of my time out riding my bike and going on lots of adventures and getting out of my head a bit. I'm naturally a person who likes a bit of time to myself, even if it's just for half an hour can completely change the game and sort of forget about the condition which I think can be quite important to just forget about things for a while."

Based on your own experiences, what advice would you give people?

"Something that can be really helpful that did take me a while to get to was kind of communicating, and I know it sounds very basic but when I was first diagnosed I was very much of the mindset to push it away, not deal with it, head in the sand, I don't want to go anywhere near that because it's scary and it can be this really life changing thing or feel like it's going to completely change everything and of course things do change but by learning how to articulate that and talking to people that I trusted and was close to was really helpful to kind of get it off my chest and you can obviously if you need to progress that through counselling or therapy, which again I found incredibly useful just to come to terms with it but communication generally just with people around you, people knowing that you've got the condition, you're going through something that other people probably won't be can really help take that load away from your mind and there's been a few occasions when just because I've known someone that knows I've got the condition it's made me feel less stressed, even a bit more optimistic about the future which sounds really odd but that's something that has definitely helped me throughout the years, so yeah, learn how to communicate feelings I guess."

What are your hopes for your future?

"In terms of things I can control for the future, I've been really working on just celebrating having what most people would consider having an average life. I know that sounds odd and it doesn't mean that you shouldn't have aspirations but just being able to have a nice job that doesn't drain me every day, having enough money to pay the bills and a loving family around me and that's what it's all about so I'm trying to plough as much energy I have available at the moment to creating that and challenging how I've always felt about the

future which is biggest house, job, best cars rather than the things that actually I think do matter which is being around the people you really love and enjoying the time that we are well because there will inevitably be flare ups at some point and when those happen obviously we'll get through them but it's nice to know there's that secure base to come back to so that's what I want to set up for the future really. That's the goal. And maybe a few more motorbikes as well that wouldn't hurt with aspirations"

What advice would you give to people in a similar situation to you, who are perhaps just thinking about going to University?

"I think preparation can help a lot in terms of alleviating the stress, before I went, sat down thinking about how to tackle certain scenarios in terms of not excessively drinking, but I think just go for it and it's an incredibly rewarding experience but there is obviously the culture which is very geared towards excessive consumption and lots of late nights and if that's something you struggle with which I have done for a while now finding people there, and you will find people there because Universities are huge and filled with complete diverse mix of people and you'll find people there who match you, and you'll always find a group, you'll naturally gravitate towards people who will support you in that and not to pressure yourself into behaving a certain way, doing certain things because that's what Uni should be like, you're kind of there to enjoy it how you want to. Another thing that took me a little while was actually using the help that's on offer there. Again, most Universities have a really robust policy to support you whether that's counselling or deadline extensions, extra time, extenuating circumstances, it's all there to help people like us who have conditions that make it more difficult to do the Uni work so just because we've got genetic conditions it doesn't mean you can't go to Uni if we want to. There might be a few extra speed bump whilst we're there or along the way but it's so worth it and there's so much support you can take even if you don't have friends and family that can support you there are so many resources that they'll be able to offer you and make it just as enjoyable as someone without. So just go for it, you won't regret it, it's so much fun and incredibly fulfilling in so many ways so I wouldn't change it for the world really. And go into halls, not a shared house. That's not the way to do it."

Tell me about your relationship with AMEND and how important the charity is to you?

"I became the youth trustee for AMEND after attending quite a few of their events as a youngster. I'm only 25 which still counts as young but I spent a lot of time connecting with people my age who were having a similar experience which again I hadn't experienced until going to one of the events that AMEND had organized and that was kind of really bolstering because it can be quite lonely sometimes feeling that no-one else really gets it. So again after the last information day I set up a little Young Persons WhatsApp group where a few of us can chat and catch up and we can regularly give each other support and it's a very unique thing where we all have an MEN condition, we're all supporting someone with an MEN condition and it's kind of a little wealth of knowledge and solidarity that stemmed from AMEND's information days, so it's a really nice, safe space really where we can talk about these very unique problems that people with genetic conditions have and that's been incredibly helpful, just feeling like you're not alone. There's a lot to be said for how good that can make you feel and how nice it is to know that there's a group of people that are kind of a text away if you need it."

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