

Brad – My Story – MEN1 (2021)

When did you first start getting symptoms?

“So, I didn’t start getting any symptoms for any sort of problems really until my late teens. It all began when I was about 11. I was in year 6 and I was doing a specialist maths class, I was quite advanced in maths and the teacher pointed out that my eye sight was deteriorating and we all thought it was just, sounded a load of rubbish to be honest and he said go to the opticians so I did and about a month later the opticians wanted to see me and said that something didn’t seem right, there was something on my eye, on my optic nerve so I went for an MRI about three months later and they said it was all fine and 4 hours after the appointment my mum had a phone call, so I was 11 and I got rushed in to Southampton General Hospital and the next morning I was in theater having my pituitary operated on. Again that was all fine, I didn’t have any other symptoms until I was in my late teens. My teeth started to break, even though I was looking after them. I play rugby and football, so like I didn’t have any broken bones or anything like that so sort of it happened quite quickly. I was shortly diagnosed, just before my second op which would have been the parathyroid and yeah, again, didn’t have any other symptoms for a couple of years and then my pancreas started playing up, and my sugars would play up and I’d have hypos and stuff like that.”

What led to your diagnosis of MEN?

“With the most traumatic experience with it, all my problems have definitely been the pancreas. They diagnosed me in my late teens, so I was like 17/ 18, just leaving college and then keeping an eye on everything. I was having scans every year. Whole body scans to check my bone density and my head, my pancreas, my thyroids and then I didn’t really have any issues with my pancreas and the hypos until I was about 23 and I started recognizing that when I woke up I’d have slight shakes and I wouldn’t feel quite right and it sounds weird, but not quite totally in my body. So, I’d wake up and I’d be shaking and half asleep. I wouldn’t remember certain things but the real problem didn’t start until August 2019. I was caring for my grandparents because my grandfather had a stroke, I was working early mornings in a food warehouse in a freezer. I’d have to get up at like 3 or 4 in the morning and start at 5. Luckily it happened on my day off and luckily it was round my grandmothers but I started to have my hypos then so I went to bed at like half nine, 10 o’clock the night before and I didn’t wake up until around 1am which was quite unusual bearing in mind I was quite the early morning person at that time. So, she had to call a paramedic out. They came upstairs and I was totally not with it. I wouldn’t respond to anything so they gave me my emergency cortisol injection which is what I have to have if I’m ill just due to the pituitary tumour affecting my cortisone levels and then they eventually woke me up and went into the ambulance and over to Queen Alexandra Hospital in Portsmouth and I stayed there for 5 days and they couldn’t figure out what was wrong with me. I got sent home and then I didn’t have another hypo for a month maybe six weeks but at the time my grandad was getting better, I then had to move back in with my parents because I wasn’t well and stopped caring for my grandparents and then one morning my uncle decided to turn up and take my grandfather out for a pint down the pub and he said do you want to come and I said, OK so I went upstairs for a couple of hours kip because I was tired and I woke up, again around 1am but again I was not with it. According to my grandmother I’d come downstairs a couple of times having conversations. I was snappy and quite aggressive which is quite unlike me. I’m usually quite a chilled person and patient and understanding so to have these hypos where I was aggressive it was quite upsetting and traumatic. I can’t really explain it,

just not me and then it started to get more and more frequent leading up to Christmas in fact by mid-December I was having them every morning and my mum and brothers would have to hold me down on a bunk bed that I'm sleeping on, I'm still sharing now by the way just due to lack of space in the house and the fact that my younger brother has to work mornings, yeah they'd have to hold me down and inject me with a hypo kit to release emergency sugars from the liver or kidney I believe and then I'd slowly come around. I haven't had a hypo for almost. It's got to be coming up 14 months now but yeah, the last couple of months before the second pancreatic surgery I was getting very aggressive, took a swing for my younger brother, he's quite big so he can take a punch so it was very traumatic and I've still got the shakes now from it."

When did you actually find out you had MEN and how did you feel when you got that diagnosis?

"So, I got diagnosed when I was almost 18. At the time my hospital team didn't really know anything about MEN1 so they were just as new to it as I was. We got given a couple of booklets to explain stuff to my younger siblings. I suppose due to the lack of knowledge about it I was quite ignorant of it for a few years. I didn't research it to be honest. After a year of not really getting anywhere I just gave up and then the pancreas problem started and I sort of had to get my rear back into gear so I suppose I was quite negligent, being at that age as well, naïve you think you know best, you think you know what you're doing, you're 18 and you're an adult. It certainly gave me a kick."

Tell me about your recent surgery?

"So, my most recent surgery was actually 8 weeks ago yesterday. My most recent surgery was called Whipple Surgery. It's where they remove the rest, I think I had about 30% of my pancreas left, it was still managing to digest food properly so fats and proteins and oils and apart from the actual tumours called insulinomas which over produce insulin, my sugars for the best part when I'm awake were very good, it was just when I was sleeping the surgery itself was taking place when I was supposed to be doing this filming explaining my story and giving awareness and what it's all about, how it changes you and stuff. Obviously being ill I couldn't do it and I was in hospital for 8 days. I shouldn't have been discharged for another one or two weeks. I was on some kind of rapid recovery programme, what that means I don't know whether I'm just a miracle or if they wanted me out of the hospital because I was doing the nurses head in. So they removed the pancreas and the duodenum which is sort of the beginning of your small intestine. They also had to cut away the tubes that attach the liver I believe, and the gallbladder, but I'd already had that removed and all the bile ducts - they had to stitch it all back together. I'm still not eating properly, one meal a day but it is what it is."

How does your MEN affect your day-to-day?

"It doesn't. Not really. Not in my day-to-day activities apart from where I had the pituitary tumour which squished my optic nerve so therefore I'm partially sighted. I'm blind in my left eye and I'm half blind in my right eye. People still don't seem to understand, well they shouldn't have to understand really. There's no reason for them to understand I suppose. It's one big part of acknowledging the whole disease is that people shouldn't have to understand but I can't drive so travelling, that impacts me. When I first finished college and managed to go get myself a career and then obviously, I got deemed unfit for work, so I had to chuck that away so career wise its definitely damaging trying to find a job where I can get there within an hour just using a bike or a train or a bus etc. If I was driving I could easily work 40/50 miles away but with being partially sighted it's not an option so everything I do in the future I've got to think heavily about, if I had full vision it would be as easy as look for a job, there's one 30 miles away, OK, I will apply for that, whereas with me, I've got to see where it is, I mean it could be 10 miles away and that would be fine because I could get

there by train but then it might be a long walk from there and I might not get there in time so there's a lot of disadvantages to it and I suppose that's the only real way it impacts me. I've just newly become a diabetic due to the removal of my pancreas so I've got Type 3C diabetes. That doesn't really affect me, not during lockdown anyway I mean I'm quite into my fitness. I know I don't look it due to the high sugar diet I was on but now I've lost 3 stones since November, but diabetes doesn't really affect my day. I'm now enzyme insufficient as well. I'm on Creon which is an enzyme to digest, fats, proteins and oils. I suppose that does affect me but not all day, it's just when I eat so I have to take them with everything that I eat, the same as with the insulin. I suppose the only reason it affects me is because I've always had trouble taking larger tablets so yeah, I suppose going out and eating in a restaurant and something like that is going to take some thought in the future when we're allowed to go do it again.

Tell me about the job you had lined up and couldn't do because of your MEN?

"To start off with I'm still very bitter about it now and again as I was saying before how people shouldn't understand but yet in another aspect they should because it was my dream. From an early age, I'd say 13/ 14 I knew that I was good with numbers. I enjoyed working with numbers which is really odd, but I decided from that age that I would most likely be working in finance, dealing with numbers, accountancy, tax, stuff like that so I had my heart set on it. I come out of school when I was 16. Didn't have the best GCSE's I had to have a specialist sats because I had to have enlarged papers and my exam papers were black with white writing and white with black writing and stuff like that, and also I didn't manage to complete all my exams just because of my eyesight but I came out with enough to do the courses that I wanted so I went into College to study financial studies and management and I also did Business studies and administration and then I also did a computer literacy course as well so I knew all I needed to know about computers and certain programmes that I'll need to use. As part of the financial studies course, I did work experience for 6 months 1 day a week at a private bank and I'd have to use excel, manage peoples' accounts and stuff like that which was again very useful and then in my second year when I turned 18, I finished my course and I passed and I got a diploma and stuff like that and then from the International school of finance I saw this job. It was an apprenticeship, good money per week at the time for my age as well. I think there was only something like 200 applicants as well across the county and they sent me an email saying you've got two types of interviews you've got formal and they gave me a second interview and they said it was an informal interview. At that point it had been reduced from 200 applicants down to like 15. Me being quite cocky and naïve at 18, I'd go suited and booted to that one as well, but thankfully that's what got me the job. A week later I was doing some shopping with my grandmother over in Portsmouth. She was taking me out to have a spot of lunch and I got a phone call from the employer saying I've got the job, and I was asked to start in a couple of weeks. I'd have a guaranteed job at the end of the apprenticeship which was two years so very good money as well for a 20 year old and we finished the call and I carried on shopping with my nan and then about an hour later I had a phone call from the specialist at Southampton General and they said that the tail end of my pancreas was riddled with tumours, I think they said they spotted 16. They weren't big but they weren't exactly small either they were 1 cm in diameter and then they basically said am I working and I said no and they said you're now classed as unfit to work or uninsured to work which, I don't know how that works. I explained the situation and they said to phone up the employer and see if they could hold the position for me until after whatever I had to have done which was, the operation was dealt with but it turns out I waited about 4 years for that operation to be done and by the time I'd had it done the position had been filled and I didn't get it, so I never actually managed to start, well I suppose I did sort of start my career I got the job it was virtually in my hand but I never actually walked through the door, so yeah I'm still very sour about it."

That must have been a difficult day. And have you been able to work at all since that day?

"I have, but literally a year at a time, so yeah I have been fit to work. So I had the first pancreas operation just after my 22nd birthday. I was fit and healthy and ready to go 4 months after that so, luckily enough I had friends and family in places and I managed to get myself a job at the local Co-op, stack shelves and serve the customers and stuff but it was handy I enjoyed it. Obviously it wasn't what I wanted to do but it was a means to an end financially and you do what you've got to do and then I decided that I needed more hours because I was only getting about 8 hours a week and I needed money, there were things I wanted to do with my life and you know, at that moment I couldn't get back to the job I wanted so I applied for somewhere called Food Warehouse and then I'd work 16 hours a week there in a big freezer out the back man handling cages and deliveries and stuff like that which I enjoyed actually because it was a bit of a work out and working in minus 30 degrees even though it seems uncomfortable it was quite enjoyable. It's a different sort of cold."

Tell me about your work goals now since you have re-evaluated your life?

"Since having the latest operation it has affected me health-wise, in so much as I have got to change my lifestyle. I suppose I was a bad eater before but now it's got to change so fresh food, no processed rubbish and obviously being a diabetic as well I've got to learn about nutrition, what everything does and how it affects my digestion and obviously with, even though I'm having one now coke zero, usually I'd be having a tea but running late this morning but yeah, I've always been passionate about sport. I've been playing football since I was three years old. In secondary school that's where my passion for sport and learning about the human body began. Obviously, it goes deeper into it when you go to secondary school. I took sports science and PE as BTEC as well instead of GCSEs so I learnt quite a lot about that and I've done further sports science, it was never a background career choice it was just something I liked doing, even after my brain surgery I was told not to play football or play rugby because it was dangerous, and it could kill me. I was still doing it. I just loved it. I was thinking about it since having the hypos, a better lifestyle I want to get into fitness and perhaps do something along those lines. The basic step at first is to become a fitness instructor. You can do a 12-16 week's course so I'm currently saving up for that it would be good to do during lockdown as well with all this pandemic going on and put my time into something useful and again keep on learning and furthering myself and self-improvement."

What are your hopes for the future?

"I don't regret having a condition, one bit. I think it has turned me into the person I am today. I mean I change from time to time. Like I said earlier, I'm not an aggressive person but since the pancreas operation I've definitely become more assertive, stood my ground upon topics or things I want to do and definitely after this operation people have been saying I'm very assertive, sticking to my guns and I suppose stubborn but the condition has taught me what is valuable in life and what's important and even though I go on about a career and stuff like that it's not that important really I suppose that's more a self-achievement thing in what you want to do but the most important things are the people around you, you've got a roof over your head and food on the table. Just enjoy what you've got. Don't take nothing for granted. If it does affect my choices, it's not in a bad way. It's definitely had a positive effect on me. I don't think I'd be the person I am today without it."

What advice would you give to anyone watching this who may be in a similar situation? And why did you want to be involved in this project?

"It's quite hard to think about really. I suppose if I was speaking to my younger self, and that's the best way to look at it, don't be negligent, keep on top of it, keep up with your appointments. Study it. Definitely look at the symptoms and I suppose just go for it, just go for what you want because I didn't see it then but I see it now but when I did get told I was unfit to work I sort of went downhill, I wasn't depressed or anything like that I was fine

emotionally, but I suppose I just sort of gave up. I just stopped learning new things, progressing and stuff like that, you've just got to keep on carrying on whatever it throws at you just battle through it. There will always be another hiccup with this condition but again, sometimes it lasts a while, sometimes it may only be a month or a couple of weeks or a few days. Just keep on at it and do what you enjoy, keep learning to take your mind off it definitely, but yeah keep yourself busy I suppose that's definitely a very good way to look at it. Keep yourself busy and don't even think about it. Just think about what you have got and not what you haven't. I wish I'd looked at it at the time. I was very stupid, and I was unhappy, I just didn't see it."

What does AMEND mean to you?

"Since the second pancreatic operation back in January 2020 I have definitely upped my game and I started speaking to people my own age because I thought most of the people living with this condition were fairly older, so I thought I was quite alone but, we've got a WhatsApp group and I speak to them every day, they're like another family now. It's a great place to speak to people about your condition problems but also, we've got to know each other on more of a personal, friendship level. So, I suppose what AMEND means to me, I can't put it in one word but It's like having another little family and it's also something to take my mind off what is going on and put my time into to help others just as young, or older or younger than me and again with this video if it helps anyone then I know I've done something right. Something good."

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