

Sarah – My Story - MEN 1 (2021)

When and how did your diagnosis come about?

“I was diagnosed in 2004. I was just 10 years old. It was just testing from blood results because my dad found out that he had it and me and my sister were tested to see if it had been passed down genetically.”

How did you feel about the diagnosis?

“I was too young really to understand it really but I didn’t enjoy the experience of having a blood test but I just used a Where’s Wally book to hide my arm and then we made a day out of it so me and my mum and dad would just go to Bella Italia or somewhere. It wasn’t really made a big fuss of, so I didn’t really understand it or have to, I just had to have a blood test every year and that was it until I had to start having problems myself.”

At that time what did you know about the condition?

“When we were diagnosed, we actually knew nothing about it, my dad was just really poorly, it was really a known thing to what he had it was only when they put two and two together, but AMEND wasn’t there yet, he didn’t really have much support. I got it explained by a doctor that it’s like an instruction manual and I’ve got some pages missing so the table I want to build might have, like not all the pages there but it might not need to build it at the same time so something could go wrong if it needed to build that table but it might skip that table altogether and not ever need it so it’s like an unknown future thing really because it affects every MEN1 patient differently.”

When did you first experiencing symptoms of the condition?

“I had an ovarian cyst when I was 17 so it was just after dad died so it was misdiagnosed for a good few years so by the time it came to having it out it was quite big, but they found that by scanning my pancreas and seeing that my organs were pushed up and squashed and I was struggling to breathe by that time and I just had that out but when I went into hospital they didn’t know whether to put me into the child unit or the adult unit because I was 17, it’s like borderline adult/child so I went into the adult unit and mum was allowed to stay in overnight which you can’t usually do in an adult ward, they thought I was like a child as well but yeah, it was OK but the only thing that was hard was communication. If they ever rang, I was too young to answer the phone but mum wasn’t allowed to know because I was an adult at the same time but then I was also a child so it was the communication that was the hardest thing because I was allowed because I was allowed mum there to care so that wasn’t as daunting but its more worrying if you don’t know whether you’re here or there.”

Tell me more about the misdiagnosis being put down to grieving for your father.

“At that time, I was told, because at first it started with digestion problems and I was just really uncomfortable, and I started looking a bit like I was having a baby and stuff like when I did my shoe lace up I found it hard to breathe and I danced a lot and that stopped my dancing because I was struggling to breathe and catch my breath a lot so I was just getting unfit really. I was getting heavier but I was eating less and I was rolling around in pain every night, like it was just getting a bit out of hand and I was just kept being told that I had digestion problems and I was ordering all this different medication and stuff online and none of it was doing anything and then I went for my MEN screening and they realized that something didn’t look quite right and they told me I was too big for the scanner but I’m 5’2” so I was like, I’m definitely not too tall or anything so I knew something was wrong but they can’t tell you straight away you’ve got to wait for a phone call so yeah, I just had to wait for

that which was quite worrying, and makes you feel quite sick all the time but yeah and they had me in pretty much straight away after that and I had to have open surgery to remove it because it had been left too long.”

Tell me about the procedures you've had up to now?

“I've had a lot of operations, and they've all got quite confusing names, so I'll just say them in kind of human words, but I've had Ovarian cyst removal, luckily I've kept everything from that, it was just the removal of the cyst, I've had my left adrenal gland removed, I've had two thirds of my pancreas removed and then this year I've had a carcinoid tumour off the bottom of my lung and three and a half parathyroids out.”

That's a long list, and you're still young so how does this make you feel?

“I find it quite upsetting really but you kind of just have to get on with it but finding people who are in a mutual situation has helped a lot because I feel quite lonely about it because in my house it's just me, and my friends and family don't have it that live here so I don't mix with people who have problems every day whereas I have to wake up with it every day and it affects you, especially when it's like, it causes little diseases within the disease like when I had high parathyroid hormone and I've got osteoporosis, but because I'm young you're supposed to look fit and healthy but no one knows how you really feel and I get quite paranoid about that, I get quite a lot of anxiety but I'm kind of used to it, it's just how I have to live so.”

What's one of the biggest issues for you?

“Because it hasn't got the word cancer in it, people think it's not as bad as is and like, it could be worse or just like get on with it or, sometimes I feel a bit like a running joke because it's so normal for me to be going into hospital and having procedures or an operation, people just kind of brush it under the carpet and they're like oh, you'll come out fine the other end but sometimes you kind of think you can only go through so much in life, you know not every, it ends somewhere, you know you can't keep going it doesn't make it any easier, every appointment is different anyway because it's all different body parts and I'm in 5 hospitals so it's a different experience every time and obviously having a different wound, or a different surgeon even can make your whole experience completely different.”

How do your scars affect you?

“My scars affected me from quite earlier really because obviously when I had my first operation it was an open wound which was quite large and I was just going to Uni, so everyone was going on nights out and wearing crop tops and stuff and I've never been body confident like that anyway, but if I wanted to be it was at the back of my mind that I just felt that I couldn't wear that kind of thing and just like every day I have to get up and look at them and I'm not a fan of them so it upsets me and I have to turn a blind eye and then when you go on holiday like people are wearing bikinis and I work hard to be fitter and go to the gym and stuff but I feel like my time's not used properly because however skinny or whatever I am there are always going to be scars everywhere and since, this year actually, now I've come to a point where there's not an angle of me that you can look at where you don't see a scar and I find that a bit hard but it's only just happened so I've got to get used to it, and we've been in lockdown so I haven't to expose anything just yet but I've put a lot of my wardrobe away since my last operation but that's quite hard and I think, it's not so much that I'm bothered about what everyone thinks I just don't like them and people do stare, like people say they don't but they definitely do.”

How do these feelings affect your relationships/friendships?

“It takes me a lot to trust someone to show them my scars and to tell them all about my MEN, like I can tell them the surface of it that’s fine but to tell them detailed information, especially if they walk away. I seem to lose friends and relationships through operations. It seems to have happened the last three times, whether its coincidence I’m not sure but you open up to someone and gain trust quite quickly because you put, well, it’s basically your life and then when you go into hospital and wake up and you’re in recovery, I think when you’re home is probably the hardest bit, when you’ve just got home from hospital because you’re not coming off all your drugs and stuff but you can’t really do much and you rely on everyone else. It’s like being in COVID but like constantly through your life because you keep going into lockdown and then you come out a little bit and go back in a bit and you rely on everyone else so if no one comes to you or takes you anywhere you’re pretty stuck and all you have to talk about is your appointments or your, the only thing you do is go to Hospital and people seem to get bored of it or they’re just not interested anymore which can be quite hard because it’s your life really and until you come out of that and get back to work and stuff you can’t really do much about it but I just seem to lose people which is quite upsetting but you have to try and think you wouldn’t lose them if they cared, so, that’s what I’m trying to tell myself at the moment but yeah (14.28) it does put things into perspective a little bit. I think some people don’t understand it, so they run away because they don’t know what to think or say.”

How has this/does this affect you emotionally?

“It’s quite upsetting especially with relationships and I get quite embarrassed and a bit ashamed that I have opened up because I have this thing in the back of my mind that people are walking around knowing that I have these difficulties or feel this way, or look this way and that’s quite personal to me but they’re not a part of my life any more but they still know and could tell anyone, they might not tell anyone like I’m not saying they do but I’m quite an anxious person and I overthink everything so I always get worried that people know and people could use it against me at some point, but as I’ve got older I think you just care less when you’re older I think. It’s childish of people to do that so as you become more of an adult that’s hopefully I can just get through, but it also shows who your real friends are which is so nice because you can, you do get the opposite where you get lots of love from the people closest to you and get you cards and visits and get you flowers and stuff and there are people who will take you out and check up on you every day. Even if someone just messages you every morning to make sure you’ve got up OK, just little things to me are more important. For someone to acknowledge you’re maybe not feeling so good or that you’re on your own but it can cause a lot of disappointment because sometimes you think people will be there for you and they’re not but then you’ve got to remember that everyone has got a busy life as well, but you’re just stuck inside and because it’s constant, it’s not just a one off thing that happens quite a lot that’s why I notice them more.”

Is it difficult being a young person with MEN?

“It is hard because even when you’re in hospital I’m always the youngest on the ward by like at least 10 years. I’m just like with really old people but it’s something I expect now because it happens every time but it’s kind of like as well when you’re travelling, if you’re really tired, if I said to someone can you get up because my bones are aching people would look at you funny and stuff like that you just have to bear with it, you just have to put up with a bit more and get through it otherwise people can judge you, it’s like never judge a book by its cover but everyone does it’s just how it works really isn’t it.”

Describe what your life is like day-to-day

“At the moment I’m recovering from a parathyroid operation which means it’s to do with your calcium mainly and you’re, basically MEN is to do with your hormones, so hormones are imbalanced quite a lot. Every day I just get up, I don’t have to take many drugs at all. I’m really lucky at the moment but I have to take Creon when I eat and I just kind of feel bloated and a bit sick every day to be honest but when I had hyperparathyroidism I felt really poorly and I had a cloudy head, couldn’t concentrate, my bones and muscles hurt every day and recently I’ve been getting quite a lot of bone pain. I’m recovering so it’s just calcium feeding back into my bones but things don’t recover straight away after an operation like it has taken me a year to build up my shoulder again after it being cut, so it’s like constant building yourself back up every day but you just have to do it and live a normal life and look like everyone else because you’d never get anywhere. If I stayed in bed every time I felt ill I’d probably never get out of bed. There’s always something but it’s just normal, so that’s my normal.”

How does taking Creon every day affect you?

“So, I take Creon when I eat because it helps to digest fat, protein and carbohydrates. There are things I can eat without it, like fresh fruit and veg and jelly but I don’t actually like jelly so that’s not so helpful, but I feel I have to plan my meals because, everyone is different who takes it, especially after talking to other people with it, but I have to eat a low fat diet and take 4 with a meal and 2 with a snack. But if I go out for dinner, like to an Italian or something, I just have to be careful what I eat all day because if I eat a load of cheese or something then I’d struggle to eat a creamy meal, it just really upsets my stomach and not feel very well and bloated. It’s annoying because I can’t really be spontaneous. If I go for a walk to someone’s house or walk past a café and I haven’t got my Creon on me I can’t have anything to eat. If someone says, ‘Do you want to stay for dinner?’ I’m like, I can’t because I haven’t got any Creon, but I usually have it in every coat and my car and every handbag but it’s impossible to have it all the time especially when it’s hard to get from the chemist so you can’t always have loads of tubs of it.”

Tell me about your friendship with Claudia and Brad and why that is so important to you?

“We haven’t actually known each other that long but when we started talking it’s like instant understanding because we just get each other and we do check up on each other, but you know when to push it and when not to. No one goes mardy if you don’t answer but at the same time they know to keep making sure you’re there or if you’ve got an appointment and you tell them it’s not attention seeking it’s literally just a letter that you’ve got, like I got one today and I spoke to Brad about it and it wasn’t attention seeking it was just something that happened and it’s nice to have someone you can tell so that someone else knows but it’s a normal, it’s just acknowledgement and if you ask questions and stuff they know the process so you don’t feel like you’ve got to say I feel like this because we all just get it and I think that’s really good and especially with the Creon because I’ve struggled with that for a long time and just to know that other people are on it. I don’t want them to be on it but it’s nice to know that I can discuss that with someone else and just see if we can help each other with food and just how we feel and compare symptoms and stuff and I think it’s best to learn from experience because the doctors have degrees and masters and stuff but they don’t know how you feel.”

How has AMEND supported you?

“AMEND has been really good actually because I joined a year and a half ago and since then I have met, or can speak to a lot of people and when we have the big meetings where, you just meet loads of people under the same umbrella and in the same boat and you can discuss your surgeons and get loads of information from all the different sections and

meetings that they have and just socialize with people that are the same as you as well. It's not just for patients it supports carers and family and friends and then there's the other types of MEN and stuff under the same umbrella as well with the endocrine diseases and it's just good to know there are other people there. Obviously we have the young persons' group as well which has been really good because we're all the same generation, in the same situations in life so we can see how everyone is progressing in life, it's very comforting to know there are people you can just message at any point and there's groups on Facebook and stuff, you can just scan it and read other peoples' symptoms. If you don't want to speak out, you don't have to."

Do you worry about the future?

"When I was at school and Uni I had my operations and appointments in holidays and at weekends so that it didn't affect my education and then after recovery that was when I went back so I was fit enough to be back at Uni again, but sometimes I feel like I'm living to go into Hospital rather than staying alive going to hospital to live. So I feel like I'm in hospital more than I'm doing anything else, but the last few years have been quite full-on with my MEN. Hopefully that's going to change now. We'll see but I do worry about the future because my dad was very poorly with it and he passed away, so I know how it can be. I also know that some people are watching and waiting and have never had an operation so it can be positive as well, that's why we have to use the positive sides to get everyone through really and that's why it's nice to talk to Brad and Claudia as well because we can egg each other on. I do worry about planning my future because you've got to show a new partner your scars and think about family planning. I'm 26 now and I feel like I'm running out of time because I wouldn't want to pass it on to anyone else so you can have PGD and stuff but that takes time and I want to get my career, buy a house and if you want to make a family as well it's going to take time and I feel like I'm running out of time."

What advice would you give?

"I'd say only you know how you feel. A lot of times I felt that I've not been heard or listened to or understood and struggled with quite a few operations that I have had to push for, like my last one; I had to source myself and I'm not someone who would eagerly go for an operation at all, but I just felt so unwell. You've just got to make sure that you're heard because only you know how you feel and if it's not your normal then you know that something is wrong, however much someone says that you're fine, you're not, because it's an invisible disease so that says it all really. I always wish I'd asked more questions and voiced my opinion a bit more of what I think or what I don't understand because then at least whatever happens and you're satisfied with what happened you can learn from it and move on from it. But if you're not happy with what the outcome is then that's when it can make you quite angry and you overthink it a lot and what could have been different or who could I have spoken to or why did this happen but if you know you can kind of get through it by just getting better but the biggest thing is just to talk, especially to people with the same disease and join groups, it's been the best thing I did. No one really understands it unless they've got it so even the medical people, there's not enough information about it, they don't always understand what you're trying to say, even your endocrinologist. Learn from experienced people rather than just reading facts and figures. Just because your levels and scans show one thing it doesn't all tie in all the time, you've got to listen to people."

Why did you want to take part in this project?

"It was important for me to take part in Project Rollercoaster because having something like MEN1 is quite negative but to share it and to make people aware of it is a positive twist on it so having something negative and turning it into a positive to help everybody else."

You've just got to accept it and get better and look after yourself really because you can't look after anyone else unless you're OK yourself.

In the future I hope that my parathyroid operation was my last for a while. I just need a break really to try and get a better career going and sort my adult life out and kind of live more of a normal life than going into hospital all the time. Obviously, I'll have my annual MEN check up's and screening but hopefully my results will be fine. There won't be anything that needs to be done urgently."

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