

# Claudia – My Story – MEN1 (2021)

---

## ***When were you first diagnosed and how did that come about?***

“I was diagnosed when I was 17 so 5 years ago. I was tested because my mum tested positive for MEN 1 after she’d had my younger sister. My mum didn’t know she had the gene at all until after she had my sister in 2004. She had problems and that’s to do with her Parathyroid, so she had those removed, and my nan had the gene as well which was obviously passed on to my mum, and my nan’s mum died of a stomach ulcer which we now think is MEN 1 related. My nan’s siblings also died of cancerous tumours, etc, so quite possibly they were MEN 1 related as well.”

## ***Tell me about the day you went for the test.***

“The day I went for my test, I went with my friend and my mum and dad and we got the train to the hospital to see the head of the Genetics Department, and I went in with my dad, and I remember my mum being really upset about it, and I was just like, I don’t understand why you’re upset, like, nothing is going to change. I’m going to find out I’ve got the gene and that’s it nothing is going to come of it, so I went in the room with my dad and the Geneticist said ‘you’ve got the gene’ and I was like, ‘oh, right, OK’, and got up and walked out, and we were going shopping afterwards and having lunch and then my mum started crying and my dad was quite upset too and then when they started to tell family, my family were upset and the Geneticist said that I would have to have a first set of scans just to see if there was anything going on. She didn’t think that anything was going on but that’s what they routinely do so she sent me for my first set of scans which were in the Children’s Hospital and on which, my first scan did show the lesion on my pancreas.”

## ***Tell me how quickly everything escalated.***

“So, I went for the scan, well I went for my blood results and thought, yeah it was a blood test, and I was a child. I was 17 at the time and things like that were nowhere near the top of my priority list. Whether naïve or not informed enough, I don’t know. A couple of years prior to that my nan had, had the Whipple procedure done and I’d watched her and been at her bedside in hospital and stuff so I’d seen how poorly she was. It never just occurred to me that it was the same thing. I just thought maybe it was old age and she was ill, but not that it would ever get to that stage for me so yeah, naïve as in I just thought I was going for this blood test and nothing would come of it and naïve when I found out that I had the lesion as well. I didn’t want to know. I was like I’m a child, how can this be happening to me, you know I was just wanting to go out with all my friends and we were just starting to get out into town and young farmers parties and things like that, nobody was going through what I was going through, and faced with this option of major surgery, but not just the aspects of surgery, all the bits before, the biopsy and things like that. I was going from worrying what I was wearing to a party to then having this major surgery in a short space of time.”

## ***What did you know about the condition when you were first diagnosed?***

“So, I knew that the gene could be passed down, and obviously through my mum that’s how I had the gene. I didn’t know it affected your parathyroid, pituitary, your pancreas and all the little bits in between like kidney infections. Obviously not everybody gets these. The tingling in your feet and in your hands, problems with your calcium, the long-term effects that theoretically you are at higher risk of getting cancer.”

***Can you tell me when you first had surgery and how you felt?***

“It took me a long time to come around to the thought of surgery. When I was told I had this lesion I wasn’t in a great place. I hated everybody. I was angry. I wanted someone to blame. Why have I started this long journey? Why did I even find out because I felt fine before and now, I am having to do these that are potentially life changing you just think that older people get ill. So, the first stage was to go for an endoscopy in Manchester which I’d put off and put off, I actually would laugh about it and say it was against human rights to which they agreed to put me to sleep so I had that done in Manchester. It was over and done with in ten minutes but for me it haunted me for ages, and it took me about a year to come round to even doing that, and then after that, they obviously took biopsies that are more clear and because it was close to the 2cm cut off that they would recommend, they advised that I had surgery. The only surgery that I could have because of the position of my tumour as it was on the head of the pancreas was to have a Whipple which is having your duodenum and gallbladder removed and joining back up your bile duct to your stomach and obviously, they cut off your pancreas where the tumour is so it’s a major operation. For some people, I think my nan’s was twelve hours and it all depends on what surgeon you can have. I first went to see a surgeon who does the 30cm cuts right across your stomach and obviously as a young girl, I’d seen my nan have that and it didn’t appeal to me, so I wanted to get the smallest cut I could get, so my mum did loads of research and came across another surgeon in London. We managed to get an appointment with him, and he agreed to do my surgery which would mean I could have a much smaller incision, and in theory a much quicker operation and in theory the recovery time would be better.”

***How did the operation go, and what was the recovery like?***

“So, I was very lucky. It was meant to be 4 hours and I was under for 8 hours, because they did come across a complication inside. I don’t really remember much of the day. I woke up at 7.30pm in ICU with my mum and my partner Jack, and then they swapped with my dad and my uncle and then, I was poorly when I woke up. My tube had come out of my nose which was draining all the stuff from inside my body so all the fluids and stuff that fills up in your stomach that had actually come out so I was being sick and it was horrible because I was retching and I was in pain, and also because I was fighting this tube that wasn’t working but still being sick so I wasn’t great. I didn’t have a great experience, I’ve got to say not everybody has that experience and then I was in hospital for 7-10 days but I was very determined, I think obviously being young that was on my side. I was determined to get up and walk and do things for myself. I’d had really good help. There was a physiotherapist in the hospital and she came and dressed me and washed me, I was walking on a Zimmer frame a few days later and then I had my drain out and it progressed really and I went from strength to strength, yeah I did have my bad days but the most challenging part of the recovery has been since I came out of hospital. The first initial days I came out I could only eat certain snacks like carrots and cucumber, things like that because fatty foods are so hard to digest and I was frightened to eat anything really as it was making me feel sick and so my diet was very poor. I lost quite a lot of weight, I was 10 stone 5 before I went in for my surgery and I’m now just reaching 8 stone 10, so I still want to put on weight, so I’ve got a long way to go but I’m getting there now.”

***What medication are you on?***

“After my surgery they advised, because obviously because of your pancreas produces your enzymes to help digest your food that obviously now I’ve only got half of my pancreas remaining, I take Creon which gives you the enzymes to help your pancreas digest the food. When I came out of the hospital I was on that religiously and as time has gone on and I’ve spoken to my endocrine consultant, and he advised that you can just wean yourself off them as and when and you find out what food you need to take them with and which ones you don’t and some days I have really good days and I don’t take them at all and some days I

have really bad days and sometimes, like ice cream is no good for me because it's dairy and it makes me feel sick and quite often I'm sick but then I can have a glass of milk sometimes at night and that's dairy and I can be fine, so on a day to day it can be challenging and I never go anywhere without my Creon and recently I have gone back on it more just because I was starting to suffer. I went through a period where I was just being sick all the time over even healthy food and I think that's why I was losing the weight and obviously if you don't take the enzymes you don't take the nutrition out of the food to help you put on the weight so now, I'm back on them and trying to have that balanced diet. I ate quite healthy before anyway but now it's just about making the right choices because the consequence of you not making the right choice is longer than you just not taking your Creon."

***Can you expect more surgery?***

"So, I'm waiting to have my parathyroids removed and because I have my calcium tested every time I go to the hospital and my calcium is getting to the cut off range of three, so when it's on or over three, your parathyroids are producing too much calcium which can affect your bones. My bones, I have low bone density for my age which could be a result of my parathyroids are producing too much calcium which instead of strengthening my bones its making them weak because it's too much, it's like overload. I suffer from kidney infections quite a lot and that can also be a result of hyperparathyroidism, you can get calcium deposits build up in your kidneys. I don't have those but just one of the things you can get is kidney infections and just generally it can make you feel a bit funny. I have tingling in my toes and in my fingers. Normally when you've had your parathyroids removed you don't get those because you're on calcium supplements. My mum is on AlphaCalcidol which she takes once a day and that is her calcium supplement. If she doesn't get those then she gets tingling in her feet and in her hands, but I've still got mine and I still get that feeling, so I've recently just been for a scan of my parathyroids and out of the four parathyroids, two of mine have already got lesions on them, very small less than 1 cm but I've already got two lesions on them so I need to have them removed which will probably reduce my kidney infections."

***How has the surgery affected you emotionally and physically?***

"I'm not afraid to have my scar out at all. In March, we went to Lanzarote and I posted pictures online of me in a bikini and I don't think twice about it. However, obviously people do stare when you go swimming or you're on holiday because it's sideways, it's not like a caesarean like straight across it's on an angle so people are curious and I wouldn't not wear a crop top, if I was going on a night out because of it. However, I do struggle emotionally with people not understanding the concept, I used to say it was just about living in Cumbria but having spoken to Sarah and Brad they feel the same way and they have similar issues. It's like if you don't say you haven't got cancer what you've got doesn't matter, so unless you're, to put it bluntly, dying, people don't see it in the same way. People don't know what it is, if you say MEN1 or multiple endocrine neoplasia; people don't know what it is. People only know the word 'cancer', so I find it really hard to explain and in some situations I feel like people just switch off because they're like, 'oh well you're not dying so it can't be that big of a deal', and actually they don't understand. You know, I go to the hospital once every three months, but I can have scans in between that and also the uncertainty of you don't know what's going to come up on your next scan. So I wish, I've had my pancreas out now that was the main thing that it started with let's just move on but unfortunately I've got a tumour on every place that you can get. So I had one on my pancreas, I've got them on my pituitary and also on my parathyroids so the next thing for me is the parathyroids. It's never going to end and also it could end up being cancerous in the long term and what, are people then going to take me seriously when I'm in that position without knowing all my history and not accepting that."

**Do you think it's more difficult coping as a young person?**

"We don't talk about it all the day because we look well and we feel fine on a day to day basis, however, we're all at different stages so obviously my nan had the worst thing first she had the Whipple and I had the Whipple and my mum has had her parathyroids out so now I can consult with my mum about me having my parathyroids out and with my two younger sisters starting their journey now and having scans and stuff I can advise them what to expect and if, I hope not, touch wood they ever had to have the same surgery as me I'd be able to advise them but I think it doesn't matter how old you are it's hard to comprehend. It's a massive thing and potentially it is life-changing for some people."

**How are you at the moment?**

"I have had, not the best of years, unfortunately very many sad occasions but at the same time I have had lots of good things happen to me, today I have just started a new job, I'm hopefully moving house within the next two weeks to my second home so I have achieved quite a lot this year and hopefully branching out on a new career alongside my new job something part time, something for me as a hobby which I'm really excited for and I'm getting married next year so as well as this being really rubbish times and going to hospital appointments and the anxiety of waiting for news and what's going to come in this scan and waiting for a letter in the post, you know there are good things in life that you have to remember and I'm like forever grateful that every day I wake up and I look fine, feel fine and I go out to work and there's nothing I can't do."

**How do you, as a family support each other?**

"We're really open about it so we will have discussions about it. We will openly talk about each other's progression and one worry was, my younger sister has just found out that she has the gene. Personally I wasn't, but I feel like my other sister and my mum and my younger sister who has just been tested were worried about the effect it would have if she didn't have the gene, so if me, mum and my older sister had the gene, would she feel guilty that she didn't have it and we did? I'm upset that they both have the gene, I don't want them to go through what I've gone through and if it could just be one of us I would choose me all day long, but I can't and as much as I'm upset that she has the gene and I hope she doesn't feel the same way I did when going for a scan, and I hope that nothing gets revealed and she can just go and live a happy, normal teenage life. At the same time, myself, my older sister and my mum are good representatives, like many other people, of how life does go on and you can cope with everyday life and you can still do things. Yes, there are bumps in the road but at the end of the day we're all there to support each other and we all know different things because we're all at different stages."

**How has AMEND supported you?**

"A couple of weeks before my surgery another girl posted on Facebook, similar age to me and she had a Whipple but she had a cut right down the middle from under her breast, right down to her belly button and she had quite a horrific time and had quite a few complications afterwards for which I wish I'd never read the post because it absolutely terrified me but everybody puts stuff on that's what it's for but then I couldn't wait to post about my journey, not to brag because not everybody has the same experience as me and I have been very lucky, but at the same time I think it's important to show that there are positive stories out there, so I posted all about my Whipple, put pictures on there, my progression and a lady has just put on that her husband has had a Whipple, he hasn't had a good time either and she's put on every day his strength, and today he has walked and such so it's great because you get that support from far and wide it's all across the world and I wouldn't have met Brad and Sarah who, right now in these past couple of weeks have been great. Me and Sarah text and speak all the time, with Brad he messaged me, Jo (AMEND CEO) put Brad in contact with me because he was just having his Whipple and so I was just

chatting to Brad and he was asking me loads of questions and, he's already had surgery but not a Whipple so it was great. I answered loads of his questions and it was good just to talk to somebody who was on the same page as me. My family and Jack, my partner, are really supportive but at the same time they just don't get it because like when I have a bad day and feel sick. It's my kind of bad day, it's not the same feeling like everybody gets if I'm having a bad day in myself. And people that have MEN 1, I feel, especially with the Whipple, will know themselves with the eating problem and stuff so it's easier to speak to somebody who is in the same position as you and then Brad put me in contact with Sarah and Sophia who I'm now on a WhatsApp with and yeah, I speak with them all the time. We don't just speak about MEN 1 stuff, like they all text me and wish me luck with my new job today which some of my normal friends haven't done outside MEN1 so that was really nice because we're like a little family, a little support group, not just with MEN 1."

***What are your thoughts about the future? Do you worry how your condition may affect your future?***

"One of the big things for me at the moment, well in time in a couple of years after I've got married is obviously the thought of having children. I've always wanted to have children, naturally, if I can even have children and for everything to be normal but obviously now I know that the gene can be passed down and that's how I've got it and what I've been through I wouldn't want my children to experience what I have been through, and imagining I was a parent I wouldn't want to be putting my child through that either, not just knowing how it can go, I think it would be extra worry for myself but having experienced it in some aspects I would not want to put my child through that and even if I didn't have the gene you want to protect your child as much as you possibly can so I did touch base with my doctor about the process of PGD and they take the egg and the sperm and remove the gene and put it back in and therefore you have a child that doesn't have the gene, hopefully if it takes which you get so many goes I think it's three goes free on the NHS and then after that you have to pay for it so it's a bit of a grueling procedure. I know quite a few people that have had IVF and obviously you wouldn't do it out of choice but that does really appeal to me. Obviously, it's not the same magic, you know that you're going to tell everyone, because you'll have to tell people you're going to the hospital and you want that support of your family, if you're ill and those extra trips to the Hospital but in the long run you'd do it all day long wouldn't you and it sounds selfish. I don't want to do it because I think, I've been through enough myself and I don't want to go through more but then I wouldn't want to see my child go through and also having spoken to my mum about it, she said if she could have done it, if she'd known about it when she had me and my sisters, she would have done it. There's no guarantee it's going to work but what if it does and the gene stops at me and my children don't have to worry about their children and so on."

***Why did you want to take part in this project? Your main message***

"The reason why I was so keen to take part is just because I felt that when I was diagnosed I had no idea of the support network that was out there. I didn't know anybody, around where I live, I didn't know anybody apart from my nan and my mum who had the gene and speaking to somebody who is on the same wavelength as you, the same age as you, just a little bit older who has a bit more experience in it but someone who you can really say how you feel because you might not say how you really feel to your mum or your dad or your sisters, especially if they're going through to be tested as well and you don't want to scare them what your thoughts are so I would just really like to provide my story as evidence that things do get better you can go through a rubbish time but I'm like how I am now and I've got all these great things going for me and also to spread the word that there is that support out there."

“The biggest challenge for me would be having to face surgery which I was very, very reluctant to do, not just the whole day but the recovery process as I felt so fine in myself and was like what’s the point because I’m not going to feel any better, I’m still going to feel the same, the only thing is I’ll obviously have this scar across my stomach for the rest of my life.”

“More with the passing of my nan I’ve started speaking to a private counsellor who has helped me a lot and to rationalize situations, but I always think, I’m a big believer in when something happens you do become stronger from that. Whether that’s you’ve got a fear of getting a blood test and you have a blood test, you then feel like you can do that and what’s the next thing but also, I wouldn’t have been able to any of this without the support of my family. My mum is very determined. She’s very positive. Everything is get-up and go and it’s going to be great and we’re going to smash this and then we’re doing this and so I do have that mentality as well but yeah, if it hadn’t been for my mum and the rest of my family I don’t think I’d be where I am now.”

“My goal ultimately would be to share my story in the biggest way possible and I’ve actually been speaking to Brad and Sarah about it saying about writing a book about it, in a bit of a comical way, not to toot my own horn but I am a bit of a laugh and I also think if you read things about MEN 1, especially googling which a lot of people do it’s like moan and drone so, a long term goal, I’d like to write a book about Whipple and about MEN1 for people who are just starting to find out about it and not just on the Whipple but about your mental health and how you can get through it and what tools are out there to help you and yeah, I know it’s not a funny situation but make some light of all of this and the friendships you can have. I genuinely believe that MEN 1 friends are friends for life.”

**END**