

Emily, Megan & Molly – Our Story – MEN2A (2021)

Emily (Mum)

What led to the girls being diagnosed with MEN2A?

“So, my sister-in-law had a problem with her parathyroid and it turned out that my mother-in-law had a similar problem and the surgeon thought it didn’t sound quite right so he recommended a genetic test and the test was for MEN and it turned out that my sister-in-law did have MEN2A, so my husband and his other sister had to have tests, along with her sons and it turned out my husband had MEN, so both the girls have got MEN2A as well.”

When did all this happen and how did you feel?

“When we had the girls tested, I was thoroughly expecting that neither of them would have it. I just kept thinking, it can’t have happened to them as well. But when we actually got the results through that they both had it I was really devastated at first but then I realized that at least both the girls had it and they can work together, and my husband has it and we can pull together as a family and deal with it together.”

How did the girls react at the news?

“They weren’t surprised at the news. I think they both had expected to have MEN2A because we’d prepared them by saying neither of you might have it, one of you might have it or both of you might have it and I think the thing was we’d talked a lot about it and what would happen if they did have it and that’s why it wasn’t tears and wailing. We spoke about it. We talked about it, we’ve talked about the things that are happening with the surgery. We don’t keep things inside, we try to speak about them so that everybody has a chance of explaining how they’re feeling rather than feeling left all alone and outside the circle.”

How have the girls been since the diagnosis?

“Both the girls are quite positive now. Megan has dealt very well with having the surgery and adjusting to life taking Levothyroxine every day. Molly is a bit anxious because she doesn’t like blood tests and needles but she’s been really good with joining in with all the appointments. She’s just waiting for her surgery, so that will hopefully be next year.”

Can you tell me about this year and what it has been like for you all?

“It’s been a really unusual year. We found out that my husband has MEN2A in about February. We had the girls genetically tested in February and then we got to April and got the results and then we had Megan’s surgery before school went back in September. She’s taking GCSEs next June so we really wanted to get her surgery out of the way and my husband is due for his surgery next week so it has been a bit of a rollercoaster, we’re still on it but eventually the thing will stop and we’ll all be able to get off.”

How are the girls doing generally?

“Generally, the girls are quite happy and positive. Going to school and carrying on with normal life, with their friends when they can be, and we are just doing our normal things as a family as much as we can.”

How do you support each other?

“As a family we tend to sit down every night to dinner together and we have a lot of chance to talk. Often the girls will say, ‘Can I speak to you for a moment?’ and drag one of us aside

to speak to us but we don't keep things secret. We don't pretend that things are going to be easy because they're not, but we do try and look at things in a positive way. So things like, yes, you've got to have surgery but it's going to prevent cancer in the future is the way we try and look at things."

How has AMEND helped you guys?

"Oh, the charity AMEND have been fantastic because they have got so many resources. They sent to us a package with comic book for the girls to understand about MEN2A. They sent a load of resources about coping with diagnosis, explaining exactly what the condition was and things you can do when you're somebody who's living with people with MEN2A, because I'm the only one in the household who hasn't got it. Sometimes it can feel a bit like oh, well what should I be doing, what should I be saying? So it was really, really helpful."

What advice would you give to anyone watching who may be in a similar situation to yourself?

"OK. So, a genetic condition doesn't have to be the end of the world. There are millions of doctors and people out there who will try and help you. There are charities, and the other thing is don't stop talking to each other. When you stop talking you can't support each other. You need to tell people how you're feeling. Even if you're having a bad day, sometimes you need to say I'm having a bad day, and this is because, and then once it's all out you'll probably feel better but the worst thing is to try and go through things on your own. Talk to somebody if you can and if you can't, find a charity like AMEND who will have counsellors for you to talk to."

Why did you want to take part in this project?

"I wanted to help with Project Rollercoaster because I think it's really important for people to realise that once you're diagnosed with something that's not the end of the world. It is hard, yes. It is difficult, but you need to talk to the people around you to find the positives in things. It's hard at times but you just have to pick yourself up and be talking to the other people around you and making sure that they understand how you feel and perhaps if you can't do that then find the charity and find other people that have got similar conditions."

You must feel very proud of your daughters?

"I'm really proud of my girls. Megan had to have surgery the previous October for her appendix and another surgery in June for her thyroid and she bounced back brilliantly from both and I know that when Molly has to have her surgery she'll be just as brave, and she'll keep fighting on through."

Megan

Tell me about your condition

"I have a condition called MEN2a and it means it can affect my adrenal glands, my parathyroids and my thyroid, and the main thing is it can cause thyroid cancer, so earlier this year I had my thyroid out to eradicate any chance of me getting cancer."

How did your diagnosis come about?

"My auntie had problems with her parathyroid glands and so did my grandma before I was born and a surgeon spoke to my auntie because he picked up on it. My auntie had a test for MEN2a and it came back positive. She had it and then my dad and my other auntie had a test because it can be passed on in your genes (it's a 50% chance for each child) and so my dad came back that he had it, so then me and my sister and my brother all had to have tests and we all have it so that's how I found out I have MEN2a."

How does it make you feel?

“When I first heard the news, I was a bit sad, it’s like quite a big thing but it’s nice to know that because other people have it in my family who I know I can talk to them and it’s also a positive thing that I know because now I know I’m not going to get thyroid cancer so I will live longer.”

What do you know about the condition, and how it might go on to affect you?

“I know that it can cause cancer and growths on my adrenal glands and parathyroid but also when I have children, I will have PGD to eradicate the condition from my family and the chance to stop it.”

Tell me about the surgery you had. Were you scared?

“I was a little bit scared, but my auntie and my cousin had already been through it before me so I kind of knew the steps that would happen. I also did like a countdown to the day I was having my surgery and I made sure I spoke to people so at my school. I spoke to our school vicar for counselling and she was really helpful and I just tried to get myself in a good mindset for surgery and it wasn’t that bad afterwards. It was only a couple of days of pain and then it all just went which was good.”

Are you worried about needing more surgery?

“I don’t feel too bad about any other surgery I’ll need because I’ve already had one surgery and I think that’s one of the worst ones and I also had my appendix out so if I have to have anything on my adrenal glands, I think it will be similar to that, so I’ve experienced things like that and I know that the hospital staff are very kind and compassionate, so yes.”

What’s your life like at the moment?

“Since I had my thyroid out, my medication has been making me sick in the mornings but only for two hours after I take it so I’m fine for the rest of the day but the doctors are trying to sort that out at the moment but other than that everything is fine and I know that if something was wrong I could go to the doctors and chat it through with the rest of my family because some of them have had the surgery.”

Do you know how your condition might affect you in the future?

“Obviously the main risk was the thyroid cancer. I mean I could get growths on my adrenal glands or my parathyroid but they’re not cancerous so hopefully it won’t be too bad and I might need to have my thyroxine adjusted as I get older but that’s just a minimal thing which can be fixed easily.”

Tell me why you take levothyroxine?

“I take levothyroxine because I don’t have a thyroid anymore and your thyroid produces thyroxine to balance certain hormones in your body but because I don’t have a thyroid, I don’t make any thyroxine naturally, so I have to take it myself to give me energy and hormones.”

Who supports you and how does that help?

“Obviously a lot of people in my family have MEN2a so it’s good to be able to speak through with one another about our experiences with it because some of us have already had the surgery that we needed and some of us haven’t so it’s good for people who have upcoming surgery to know what’s going to happen because people have already been through it and also my school were very good at providing counselling for me to make sure I was ok.”

How have your friends reacted?

“So, when I first found out they were all kind of gutted for me but said that I was going to be alright and since my surgery they have brought me flowers and things when I was recovering

and it was really nice to see people over the phone and stuff and they were concerned about me but very caring and were making sure I was ok.”

What are you looking forward to in the future?

“In my own future I would like to go to college next year and do an early year’s course to work with young children and I would hopefully become a speech therapist later on in my life.”

Do you worry about the future?

“I worry a little bit that my sickness doesn’t grow or if I do have to have another surgery of how it would affect me but I know that I would be able to catch up because I’ve caught up with things when I have had past surgeries so I think I would be able to catch up.”

Do you worry about anything in particular?

“I know that if I have children, I would try my best to eradicate the gene that would be my main concern, if I had children I wouldn’t want to pass it on to them.”

Why is it important to be positive?

“It’s important to be positive because if you look on the negative you can make yourself more unwell and you can make other people around you feel worse and it’s important to feel positive for me because obviously my dad is going into surgery. So I need to be positive for him and other people around me to make sure that they’re OK and happy.”

What advice would you give?

“I would say to try and look on the positive side, that even though you have it, you know you have it and you can eradicate a chance of getting cancer which is a really bad disease so you know that you can live longer and also just try and talk it through with someone and if you don’t have anyone then get counselling, just don’t keep it all into yourself. Try and speak to someone.”

How has AMEND helped you and your family?

“We watched some of the videos about MEN2a and we got some of the booklets from them and it’s been really helpful in explaining the disease. It was really helpful in explaining to my friends as well because a lot of things are so scientific when it comes to genes and things, but I found a very good video to send to my friends and now they understand everything and so do I.”

What’s it like to get a diagnosis like this at such a young age?

“It was a bit strange but when my dad came out that he had it I knew that there was going to be a chance that I had it, so I kind of prepared myself that if I did have it, I’d have it and I would get through it but then I also need to support my dad as well. It was a bit strange because not many people my age don’t have a thyroid but it’s alright.”

The hardest thing was my surgery because it’s just like preparing mentally but I have got through it, so I know that my dad and other people in my family will be OK when it comes to them.

Just look after yourself in general and get a good night sleep if you can and talk it through with people because that really helps not to hold it all in.”

Molly

Tell me about your condition

“Well, I have a condition called MEN2A and it can affect your thyroid and cause thyroid cancer and it can also affect your parathyroid and your adrenal glands, but I know that I have to live with this condition but in the end it will all be alright.”

What do you know about the condition? I guess a year ago you'd never heard of it?

“I know about the condition obviously that it can affect my thyroid and cause cancer but yeah, a year ago I didn't know anything about it. I didn't even know it existed but seeing all different videos and information about the gene I can understand it better and see it from a positive point of view.”

How did you feel when you were diagnosed?

“I was a little bit upset I had it because obviously I'm not going to be really happy but then I realized I can't take the negatives out of things in everything, you have to look on the positive side and after I found that I had it I knew Megan had it as well and my dad had it as well and my auntie had it and my cousin as well so most of family do have it and I know we can all stick together.”

Do you think it helps having other people around to talk to, who are going through the same thing as you?

“Yes, because they can understand me and where I'm coming from so, I know I'm not trying to speak to myself if that makes sense, it's great to have my mum to support me but having other people with it they understand your worries.”

How are you at the moment?

“At the moment I'm perfectly fine. Obviously, I'm a bit anxious about the gene but in physical I'm not that bad. I'm quite well.”

How do you feel about the surgery, but knowing Megan has had it?

“Well, it makes me feel a bit better about it myself because I know Megan was very strong and brave through it and I know she healed up very quickly and she was OK. I'm still a little nervous for my dad and my surgery just because it's the unknown, you don't really know, Megan could react differently, but I know that we're going to probably have similar reactions because we're both strong.”

Is it nice having your sister there to talk to?

“Megan just like, she can give advice better because she's gone through the surgery and all the other blood tests, so it is nice to have her there to speak to and speak about my worries.”

Have you talked to your friends at school about your diagnosis?

“Yes, I have spoken to some of my friends about it, the gene MEN2A and they've said it's quite bad but try not to panic me and people are saying I understand, like if they can understand where I'm coming from but they're not like oh my gosh it's so bad, they are more saying it will be alright in the end, don't worry.”

What are you looking forward to for the future?

“I'm just looking forward to growing up and finding me as a person and looking forward to being an adult.”

Is there anything you worry about?

"I am obviously worried my surgery in the future, I'm a bit worried about when I'm older because it can cause lumps on the adrenal glands and parathyroids and when you're older it's more likely to come, but now I know about the gene that makes me feel better."

Do you think it's better to know, than not know?

"Yes, obviously knowing is much better than finding out you have thyroid cancer and where it's come from."

Why did you want to take part in this project?

"The reason I wanted to share my story and our family story is to show people that they're not alone out there, there are other people with this condition. You're not the only one with this condition and it will be alright in the end."

Why is it important to be positive?

"It's important to be positive because if you're negative, everything seems so much worse but if you walk around with your smile on your face then it's going to make you feel much better and more confident about the gene and much more worry-free."

What would be your advice to anyone newly diagnosed?

"It's not the end of the world and I know it can be hard sometimes but what you've got to know is you have found out you've got this condition and, in the end, it's going to be ok and you're going to get through it."

How has AMEND helped you?

"Well, they are very good because it makes me feel like I'm not alone and there are people out there to support me and my family. Just knowing there are people that actually care."

What has been the hardest bit for you?

"Personally, for me it has been the blood tests. I know you should be very positive but I'm not very good with needles but just having my mum and other family there to support me I've been a lot better and it's OK."

Advice?

"Well, my advice is don't panic too much about it. Obviously, you're not going to be very happy about it but in the end, you just want to keep the smile and talk with people because it really does help especially if you have other family members with the condition and it's just going to help, and it will take a giant weight off your shoulders."

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