

A young person's experience of living with epilepsy

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SPEAKERS

Eva – medical student interviewer, Fiona – young person, Karen – Fiona's mother

Eva

Welcome to the Medicines for Children podcast. In this series, we're talking to those with a specialist knowledge of living with epilepsy. I'm Eva, a medical student and a member of the Medicines for Children team. In today's episode features a conversation I had with Fiona, a young person with epilepsy, and her mum, Karen, about how the condition has impacted their lives and the adaptations they have made along the way.

Eva

So how old were you when you were first diagnosed?

Fiona

About eleven, eleven and a half?

Eva

I think that's quite old, actually, isn't it? Most people are diagnosed a bit younger than that.

Fiona

Yeah.

Eva

How was it for you, when you were first diagnosed? How did the two of you find it?

Karen

I hated it. I thought it was the end of the world.

Fiona

(Laughing)

Karen

Knowing that she's got this condition, and obviously, I'm a slightly older parent. And obviously, there's all these... How would you put it? There's all these weird and wonderful connections with epilepsy, 'oh like she must be mad!' Or, way back in the Bible, 'she's possessed!' All that type of stuff. And obviously, how is this going to affect her future. Which it has because it has affected education, between puberty and the epilepsy, it really seriously affected her education. And it's the fact that she doesn't have any visible triggers. She can't. She doesn't know herself when she's going to have one. And I can only tell if I'm in the vicinity of her, that she's going to have one.

Karen

And also what I don't like is, you're moseying along, and everything's fine, and then 'wham bam' away, she goes again, and she has another one. You feel so bad for her. And I hate it. I really do hate it. And I told her I was going to say this. But at the end of the day, we're coping. We've learnt to cope with it. How I don't know? I think we're just matter of fact, we've got used to it, with what to do. And I'm much more open about it with colleagues and other people. Whereas, at the start because of people's perceptions of epilepsy. I never said a word. And Fiona was much, much, more open. She's always been brilliant about it, whereas I've hidden it until what, maybe the last four or five years really.

Fiona

You have managed to talk yourself into being used to it, because at the beginning, you blamed yourself for it.

Karen

Now I thought I'd done something wrong when I was pregnant...

Fiona

Or dropped me on my head as a baby!

Karen

(Laughing)

Fiona

No, that would probably have been daddy, that did that! But yeah, my mum kind of blamed herself and I used to like come out of it and she'd be like crying and stuff. So, and then I would feel bad.

Karen

But we've got over that...

Fiona

We've gone over that. I made a PowerPoint because I started having them in Primary 7 and first year was quite bad as well for having them. I did a PowerPoint and then in front of my whole year, I said, I was talking about. I did a presentation and explained what would happen, the different kinds of seizures that people get, how everybody's epilepsy is different to them. Like, like my brother has got epilepsy as well but his is the photosensitive one. He's only ever had two, so he's quite lucky.

Eva

So how does epilepsy affect you when you travel? Are you, is it okay on planes? Is there anything that you've got to do in particular?

Karen

Traveling's fine. Obviously, travel insurance is expensive. Because I have to pay a wee bit more.

Fiona

I'm sorry about that Mum! (laughing)

Karen

They are quite good in a way, because they tend to base it on how many seizures you've had in the last, say three or six months. So if we're lucky, and she's only had one, it's probably cheaper.

Fiona

Thanks a bunch! (laughing)

Karen

Whereas, if she's had four or five, it might be a bit more expensive. But she travels fine. And she has never ever had anything on a bus or a train or a plane. Touch wood!

Fiona

It tends to be before or after.

Karen

I hate saying that. Its like folk saying, 'and how's Fiona doing?' And I hate saying because I'm always that wee bit superstitious at the back of your mind, which is totally ridiculous...

Fiona

Because of that one time...

Karen

You're scared, you're scared to say it, that she's doing fine in case she has a seizure the next day or something like that? Because it happened once and you're like that, 'Oh!'

Eva

So, you're saying that you're still having seizures at the moment? Or it's still not completely under control? So how, talk me through how you found the right medication for you or how you're finding the right medication for you?

Fiona

Well, we're still trying to find the right one. I've been on... five or six different medications?

Karen

Five or six medicines? And she's on a combination of two at the moment. Reasonably high doses. She's not on the one that would affect if she was pregnant. She hasn't ever been on that one. But she's tried everything else. But she's got an appointment with epilepsy nurse next month. So she's back in the care of umm, back up here in the care of the Queen Elizabeth neurology department there. So they're good at keeping in touch with her. And I think that they're quite happy to leave it as it is because we're not having that many at the moment. But she's still having about maybe 4 to 5 a year, which is a lot, lot better.

Fiona

I get more during like see, when see, like last year and the year before, when I had more tests, they seem to get worse during that. So my mum thinks it might be stress related?

Karen

No, I don't think it is stress related. Because she can be sitting watching television in the house, and she can have one. I don't know. We just cannot pinpoint.

Fiona

What's causing it...

Karen

What sets her off. She, she could be lying in bed watching the television, she can be sitting downstairs watching the television, sitting and talking...

Fiona

Or when I can be at the top of the stairs!

Karen

But I do know that she does, she does have them when she is a wee bit under stress. We did talk to – what was Sinead again? A clinical psychologist? Or a psychiatrist?

Fiona

No, a clinical psychologist, we went to that, when it was really bad

Karen

When it was really, really bad. She was also having, like fake seizures. It was like flop, flight, freeze, that type of thing. And she was referred.

Eva

Okay

Karen

To a doctor at the...

Fiona

Queen Elizabeth

Karen

The Children's Hospital. And she gave her coping mechanisms. So she's got a whole raft of coping mechanisms to try and deal with the stress. But if we knew what caused it, life would be a lot easier, and we'd avoid it!

Fiona

Or we'd be able to manage it better.

Karen

See, 3 or 4 or 5 a year is manageable compared to what it was.

Fiona

And after I've had them. It's always, 'I want my mum.' My mum says, 'I want my mum!' I can be sitting next to my dad. And he can be like, 'it's ok Fiona' and I'm like, 'I want my Mum!' And you're at work or something!

Eva

Oh that's lovely in a way isn't it! In day-to-day life, so any average Tuesday, is there anything that you feel that you've got to do differently to any of your friends or you know, your siblings because the epilepsy?

Fiona

No, I just make sure I've got my phone with me. In case I have one and I've got, my mum and dad had, you know you get those medical alert chains and medical alert bracelets and everything. My

mum and dad had one of them made for me. Umm and because you can get them made, you don't have to have them, I can't think!

My dad's got one for his heart, but they had one made and it's got like, in case of emergencies, so it's got my dad's mobile number on it. Because my mum's at work. So if I did have one, then they know to call my dad.

Eva

Do you think it helps you feel, like a bit more independent so you can go out with your friends, and you don't have to worry about people not knowing.

Fiona

Oh no, I'm very open. If someone, if I'm going out with someone, I tell them I've got epilepsy, if I have a seizure, don't panic But I know that when people see it the first time they will freak out. Because when I first saw my brother, my dad says I was in a fit of tears, because I freaked out because I thought, oh my god, this must be what I look like. This is terrifying. It's scarier than you think. See when you see someone else have one. It's so scary.

Karen

Well see, it wouldn't scare me now. What I would say, though now, is that if she ever went out into a flat on her own, I would make sure I'd got as much... you know how you can get special equipment like kettles that, that you don't need to pick up. Like tip and tilt and pour. I'd make sure she had stuff like that.

Fiona

Epilepsy friendly stuff.

Karen

Yeah, epilepsy friendly stuff, yeah uh huh.

Eva

It's really good that they do things like that, actually, like I didn't realize that they had so many things that were like epileptic, epilepsy safe.

Karen

Yeah, I don't know where I found it now. I don't know if it was something that the hospital gave us, or the epilepsy nurse gave us. But that stuck in my mind.

Fiona

It might have been in one of the information leaflets.

Karen

And I thought that was a really, really good idea. Because obviously, if you've picked up a boiling hot kettle and you've decided you're going to have a seizure, you're running the risk of giving yourself bad burns. Because she had a kind of, spaced out one, she didn't have a seizure, she just had like an absence of it I said. And when she came out of it, the pot handle it wasn't on fire or anything like that.

Fiona

No it was, it was on fire!

Karen

It was on fire. But the kitchen was reeking, but she knew what to do. So that's the only thing. I'd make sure she had a smoke detector

Eva

So now in college, but also when back when you were in school, so every day, were there any changes that your school made for you, to try and like adapt to your epilepsy or anything like that? Because I know that you said that you did the presentation for your schoolmates. And that was really cool. But is there anything that you had to change, or they changed for you to make life a bit easier?

Fiona

Separate accommodation for exams and tests and everything. And that was about it. Because, because I was very open if someone saw me have one, they would get someone to get a teacher. And all the teachers knew because we had... Up here you get a seizure plan, like an epilepsy seizure plan. So it will explain the protocols for it, what to do, what seizures may look like that kind of thing.

Eva

That is so clever. So, so like you're your teachers would have that, and they'd know what to do if they saw you having a seizure.

Fiona

Yeah the school got a copy of that, and college got a copy of that, and we've got a copy of that as well.

Karen

The only thing was, you know how you get the high stools for the science benches...

Fiona

Yeah, that was not safe.

Karen

We couldn't do anything about that so, Fiona decided to have a seizure during science and fall off the high stool.

Fiona

I got a big bump on the back of my head for that one! At least it wasn't Home Ecc (*economics*) though!

Karen

But apart from that, that's, that's the only thing because you couldn't really, you can't have a small seat at a science bench when you're doing experiments because it just doesn't work.

Fiona

But hey, at least it wasn't a day when we were, when we were like setting stuff on fire! (laughing)

Eva

(Laughing) like with Bunsen burners!

Karen

But the really, really good thing about it was, her pupil support teacher was excellent. He was really good.

Because alongside the epilepsy, she also has this like fake epilepsy, the fake seizures that she diagnosed with. Like flight, fear...

Fiona

The fight or flight response...

Karen

Like fight or flight response. But we didn't know there was a like 'flop' response.

Fiona

(Laughing)

Karen

And Fiona would just flop! But it was like maybe a seizure, but it wasn't a seizure, so between that, the seizures, puberty, and the medicine it was like...

Fiona

Hell on earth?

Karen

Hell on earth. It was quite a torrid time. I would say third, fourth year. So when she was like, 14, 15, 16 ish, that really, really affected her academically because she missed so much school and then there was times, she, she wasn't keen on going into school.

Fiona

Yeah, it wasn't a good time.

Karen

But much, much better now. And I think the fact the medication has changed and she's matured a bit now...

Fiona

Just a bit?! (laughing)

Karen

Well I don't mean in terms of, you're still maturing, but you're not in puberty anymore. You know what I mean?

Eva

You know what, that that age is horrible anyway! I hated being 14, 15. So the fact that you were doing that and going through epilepsy, getting the right treatment, having these, like pseudo seizures, I think that's just amazing that you managed to figure it all out.

Karen

She had a couple of stays in hospital where she was wired up.

Fiona

And I've never had one! (laughing)

Karen

Well, you had one wee one.

Eva

Do you ever find that when you tell people about your epilepsy, do you ever feel that they don't understand what it means, or they have misconceptions about what epilepsy is?

Karen

I think nowadays there's a better understanding. And younger people are probably more tolerant with it. But I think part and parcel of that is because it's not visible. It can be a wee bit...

Fiona

What do you mean? People think there's nothing wrong with you?

Karen

I think that perceptions are changing, and people are more and more epilepsy aware. But I still think we need to get the message out into the schools more. And that's what we're going to be working on at the weekend.

Eva

Okay, so I know that you're doing stuff for Epilepsy 12. Can you just tell me a little bit about firstly, why you got into it, and just what it is, what's the job of Epilepsy 12?

Fiona

Well, I've got into because I've done stuff like this before, like, I'm trying to think what I did? Mum, can you remember?

Karen

Somebody asked if you were interested in joining this epilepsy youth group?

Fiona

Yeah.

Karen

And they said, aha.

Fiona

But we didn't know how we'd get into the Epilepsy 12 thing because it's normally everywhere else but Scotland! But yeah, I've been enjoying being part of this as well because it's nice to talk to other people who know what you're going through. Because, like you can talk to your friends and stuff, but they might not understand. They might not understand fully how it feels to be the person with epilepsy. They'll know what it's like to see a seizure, but they won't know what it's like to be the one having it. Because for them, it might be scary. But for me, it's terrifying. Because I don't know what's going on, or why it's happening or anything like that.

So what we're going to be like discussing and everything, is school plans for epilepsy care, so how to explain it to schools and make them awareness and raising awareness in school about epilepsy. And then the mental health for like people with epilepsy. Like their mental health can be quite bad and remember how horrible I felt and stressed and everything I was like. But when we went to see the clinical psychologist, my mental health got a lot better.

Karen

So did mine!

Fiona

(Laughing)

Eva

I know you were talking about seeing the psychologists. So just talk me through what members of your healthcare team that you see quite a lot? Because I know it's the epilepsy nurse. But just talk me through who you see when you go for an appointment?

Fiona

It tends to be the epilepsy nurse that we get our appointments with.

Eva

How often do you see her?

Karen

How often do we see her? Well when did we speak to her?

Fiona

Last year.

Karen

No we spoke to her, end of August?

Fiona

Yeah.

Karen

We spoke to her in August. Well I actually initiated that call, because Fiona, at that point was having a couple, which was a bit unusual and I just wanted to make sure we were doing the right thing. And from that, I think there's maybe a team of epilepsy nurses up in Glasgow at the Queen Elizabeth. So we found out who our actual epilepsy nurse is, and she's got her first appointment with her next month. And the consultant is probably well, since surely, we only really re-registered last year. So we've only spoken to the consultant once. Not face to face yet. So it'll be quite good when you get a face to face, because you get to know the person better. And you just can build up a better relationship.

Karen

Yeah, well, they can read your body language as well which is a big help. Rather than just...

Fiona

You're coming in with me.

Karen

Oh aye a face to face one I'll go because I quite like to meet the person.

Fiona

She writes everything down! She writes the dates and all that down.

Karen

I write the dates of the seizures and how long they last and what she's like when she comes out of it.

Fiona

Probably where it happened and all!

Karen

It's quite, it's quite funny because I've got - I don't know if everybody's got their wee own routine - but once she's finished 'seizing', or whatever you want to call it. She's always quite tired, and she's still a bit confused. So I keep going, "what's your name?"

Fiona

Or "what's my name?"

Karen

"What's your name?" And she's going, "err Fiona", "Fiona what?" And when she can tell me her name, I know she's okay. (Laughing). And then it's usually "I need the toilet" or "I'm going to bed!"

Fiona

Tends to be "I'm going to bed."

Karen

But when she decides what she's doing, it's very difficult to stop her from doing it. Like, I'm always concerned that if she stands up suddenly, she's a bit wobbly. But, oh my god, the strength she has when she comes out of it, for that, that five minutes or so. You, it's very hard to change her direction. I'd like, try to stop her from going up the stairs to her bed, "just lie here"! "No, I'm going to bed". And your like that, "right I'm coming up the stairs at the back of you, so you don't fall down the stairs!"

So we do have a bit of a laugh about it, now! Now that we can. But initially, I couldn't. There was no way in this earth that I could have had a laugh. And I think your dad is as relaxed as I am.

Fiona

No, no he still kind of freaks out.

Karen

He's still a bit, "oh my god, it's happening!" Whereas, I just go, "here we go again".

Fiona

She does!

Karen

Don't I? "Here we go again!"

Fiona

Or you're like, "Fiona? really? Again?"

Karen

(Laughing)

Fiona

After I've woken up after a couple of hours of sleep. She's like "Fiona. Did you really have to do that you were doing so well."

Karen

(Laughing) But it's banter, it's not...

Fiona

...being mean. It's just trying to make me laugh after I've been asleep for a couple hours. And then I can't sleep at the night. I don't really sleep well the night after I've had one.

Karen

And then you're always quite hungry, because sometimes you're sick. Sometimes it makes you sick. But we know what to deal with. And I keep coming back to, see if I knew what triggered it, life would be a bit easier I think. It's the...

Fiona

It's the not knowing.

Karen

It's the not knowing and then, going along quite nicely with nothing happening, and then bam! Away she goes!

Fiona

Like we got to like nine months or something.

Karen

We had nine months at one point, which was amazing. But I think the most we've just now is maybe about three, three and a half months. But that's more manageable than what it was before.

Eva

You are both just so chilled out as well. And you can tell that you just like bring a bit of humour to it, which is just, it's so human, it's lovely to hear.

Fiona

I think you just kind of have to because otherwise you'd just be so upset and so stressed.

Karen

No I don't think you have. Well not for me.

Fiona

It helps. It helps if you can just kind of get through it a bit.

Karen

It's taken me a long time to get to this stage whereas you've always been very open about it.

Fiona

I've always been very open. I had one in Tesco in NC. And obviously, someone had called an ambulance and...

Karen

Which we don't do, which we don't do, because we know the seizure pattern. But obviously, they'd phoned an ambulance and both Fiona and...

Fiona

And one of my friends had said to me, once we got back and I'd had a sleep. They'd come through to check on me a couple hours later, they'd said, "Fiona, you were really rude to the ambulance, to the paramedics". "But what did I say?" And I got told I said, "Don't want to go. I want my bed!" One of my friends had been and done my shopping for me as well, which was quite nice. But I felt so bad that

they'd said, they'd said to the paramedics, "it's fine, it's fine, she has epilepsy, she's had them before, she's just, she just needs to sleep, she'll be fine".

Karen

So it wasn't one of the group that phoned an ambulance, it must have been a customer in the store who'd phoned the ambulance. So we know, like obviously and College know, and school know not to phone an ambulance, because that was part of the epilepsy plan. Unless it went on longer than normal, or she was coming out of it and going back into it - all the usual stuff, all the information you get. So I think she was a bit short, "I'm not going to hospital".

Fiona

"I don't want to go, I want my bed"

Karen

She just wanted her bed because that's what she wants to do. She wants to go to sleep.

Fiona

And kind of recover.

Karen

Sleep is the best recovery, and it takes anything from, I would say 24 to 48 hours, to be back to normal. Fully back to normal. Depending on what normal is with you. (Laughing). I thought I'd just add that wee bit in there.

Fiona

I don't like you anymore.

Karen

(Laughing) She says she's not talking to me now. So what else do you want to know? I can't think of anything else?

Eva

I would love to keep you forever, but I will let you go. But just before I let you go, I just want to ask if you have any advice that you'd give to other people with epilepsy or their families or people who have just been diagnosed, anything that you'd like to say for them.

Karen

Don't be like me. Don't hide it.

Fiona

Don't stress yourself out about it either. If you're struggling with it, try to at least be open with your family about how you're feeling - it helps. It took you forever to get... oh no please don't cry Mum.

Karen

I just felt, I didn't support her enough at the start. Because...

Fiona

You couldn't understand it yourself.

Karen

I couldn't deal with it. And being that wee bit older, as I said before, about the madness and the possession and stuff like that. And I know that perceptions have changed. And I think it's all about, I never spoke to anybody. Maybe I should have done. And I would say if it's a diagnosis, and it comes out the blue - which it does - speak to as many people as you can to get the reassurance that, 1) you haven't done anything wrong 2) you're not at fault, you didn't do anything to them when they were in the womb and 3) just talk. Because talking helps.

Fiona

Even if it's just like, your friend or family member, or even if it's just like...

Karen

Like, I've got a best friend, that I went to college with and it took me ages before I could fully open up to her. And that was my best friend. So I think, I think if you're struggling, get as much information as you can.

Fiona

But don't go online and look up stuff! Definitely talk to...

Karen

Talk to people who are in the same situation as yourself.

Fiona

Like, I'm on a couple of epilepsy groups on Facebook as well. So if you can do that, that's helpful as well. So that you know that you're not the only one going through it. And talk to the person with the epilepsy - if it's your son or daughter, or your parent, whatever. Talk to them.

Karen

But you don't know anything about it! (Laughing)

Fiona

I don't know anything about it! But I'm still here for you mum. I still love you.

Karen

I love her, cause she knows nothing about it!

Fiona

I know nothing about it. But after seeing my brother, I can understand that it's terrifying, for the first or second time, it is terrifying.

Karen

I think that a parent who's experienced that needs reassurance, that they'll eventually find their own way of dealing with it and recognizing. Hopefully, if their child is diagnosed, then their child will have a trigger and the parents will be able to recognize it. But if you're in the unfortunate situation like us, you just have to find coping mechanisms and how to deal with it.

Fiona

And try to keep going.

Karen

I think, I think we're there. It's been a long journey, but I think we're there. I would say we've gone through hell and we've come out the other side.

Fiona

Mostly intact.

Karen

Well, I've come through hell and I've come out the other side, because I can cope and I can deal with it. That's it. We just get on with life. Everyday life's just normal.

Fiona

Maybe changed slightly or might...

Karen

Your path might change. Tweak it a wee bit. But hey ho, we get on with it.

Fiona

We're still going, we're still alive! That's the main thing!

Karen

We're still here, we're still a family unit and everything like that. So that's good. So also it's quite good, because we're Scottish. And I think sometimes everything's down south, et cetera. So it's quite nice to have been able to be part of this. So thank you very much.

Anna (Medicines for Children project manager)

Thank you for listening to this podcast. On behalf of the Medicines for Children team who commissioned this podcast series on epilepsy. I'd like to say a huge thank you to Fiona and her mum, Karen, for sharing their experiences with us so openly today. And also a big thank you to our brilliant medical student Eva for doing such a great job of interviewing. We hope that hearing a bit about Fiona and her family's experience of living with epilepsy will be really helpful for other young people in their families who might be going through similar experiences.

If you'd like more information on what other episodes are available in this series on epilepsy, please subscribe to the RCPCH podcasts or for more resources and information on medicines for epilepsy. Please visit our website which provides a wealth of information for parents and families available at <http://www.medicinesforchildren.org.uk>. On here we have information sheets for the 20 most commonly prescribed medicines for epilepsy.

If you find that your child's medicine is not on this list, please let the team know by emailing us at medicines.leaflets@rcpch.ac.uk.

Thank you again for listening.