

Epilepsy with Murray Goulder and Daniel Jennings, Epilepsy Action

Speaker Key:

- CB** Chantal Boyle
MG Murray Goulder
DJ Daniel Jennings
VO VO

00:00:00

VO Welcome to the Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

CB Joining me today on the Sunflower Conversations podcast is Murray Goulder, who has epilepsy, and Daniel Jennings from charity Epilepsy Action. Today, we are talking about absence seizures and access to venues. Welcome, both of you.

DJ Thank you.

MG Hi, Chantal.

CB So, let's get started. Murray, can you tell me a little bit about yourself, please?

00:00:54

MG Yes, no problem. Right, so I'm 43 years old. I've had epilepsy for 27 years. I'm an HR manager at Royal Mail Parcel Force. I have absence seizures, yes. That's pretty much for me. And I'm married.

CB You've got a full-on roll there. HR Manager, I know that they're a very, very busy department in any company that you go to, and obviously, the Royal Mail is huge, so let's explore a bit more. So, what is an absence seizure and when did they start for you?

MG Absence seizures are, basically, you lose awareness. I don't lose consciousness with my seizures, I'm just not sure what's going on. Mine last anything from 20 seconds to 2 minutes. When I have a seizure, if I'm moving already, I continue to walk autonomously.

I can fidget with my clothes, that can be a sign that they're happening. I can dribble. If you're in a classroom with me, I might stop, and I might stare at you. Sometimes I talk, mumble, and yes, that's about it. They're some of the symptoms of an absence seizure.

CB So, it's quite a distinction to make, isn't it, because there are different types of seizure that people who have epilepsy can experience. So, absence seizures, what you've just described, it doesn't look as obvious as the tonic-clonic, where you would fall to the ground. In your experience, what have people thought was going on when you're having a seizure?

00:02:37

MG Well, they started when I was 16, that's one thing I missed. But as I've been growing up, I've been mistaken for being drunk. One time, someone thought I was having a heart attack. But the drunkenness is definitely one of the things. Some people thought I'd been messing around. And other people have just walked by and completely ignored me.

I can understand that. I can totally understand that people would be, potentially, too scared to intervene. So, yes, that's some of the examples that I've had. Some people have seen it. Some people have noticed and helped me. But yes, that's it.

CB I would imagine, probably, that's in the minority, though, people who know about the seizures.

MG Yes.

CB Because I think you're right. If we think somebody is drunk, we're a bit intimidated because we're not quite sure which way it's going to go. There's the unpredictability of people if they've had a lot of alcohol to consume, isn't there, so that's why, basically, an awareness of this is important. Are you conscious and aware that you're having a seizure at the time? Or do people report back to you afterwards, well, you were doing this?

00:03:59

MG No, I get a feeling very, very quickly. I don't really get an aura before it happens. If I do, it's not what people generally associate with it. Some people get a smell, and I've heard people saying the type of auras that people associate with epilepsy, I'm not aware of those ones.

I get a rising sensation in my stomach, but it's, what I would say, milliseconds beforehand. And what I associate that as being the seizure, I'm told afterwards that the seizure happens afterwards, and to me, it's like a split second. Within that split second, I could be halfway down the road, which is what frightens me.

And sometimes, in a real situation, I've crossed the road and been, potentially, it could be, hundreds of yards up the road. In a couple of situations, I've almost walked to the train platforms, and that's happened three times.

CB Wow. And that's the terrifying thing, in that you've only got a millisecond warning. It's not enough time to make any action, is it?

MG No. No.

CB So, how has this impacted your life, Murray?

MG I've had to get used to it. I've had to realise that it is something that I've learned to walk with, sounds strange to say walk with this condition and grow up with it from the age of 16.

00:05:27

I've taught people about it, and that's one of the things that I think is really important is that one thing that's come with having the lanyard, and stuff like that, is I've grown to not be scared of the condition, which I was extremely scared of it at the beginning.

I talk about it all the time now and I tell people that I meet. It's an icebreaker for me now. It's one thing to tell people about it all the time. And part of my job is to actually educate people. One part of my job is people about conditions. So, yes, it's a good thing to talk.

CB Can I ask, do you know if it's ever brought about by stress?

DJ With my own epilepsy, I don't think so. And the reason I don't think it is, is because two of the most stressful times of my life was losing my parents, and both times, I didn't have a seizure once.

When I do have my seizures, when I try to think about when they happen, they can happen when I'm most relaxed, as well. So, say, when I'm out walking, and stuff like that. The places where they've happened, I'm not always stressed. I think it's actually linked in with... It can happen at any time. I think it's in a part of my brain, where it hasn't formed properly, and I think it can strike whenever it wants to.

00:06:57

CB Very unpredictable.

MG Exactly. If I have an absence seizure, dependent on where I am, and dependent on how long it's lasted, I may need to sit down and take five to ten minutes to just get myself back into sorts. Take a break. Just wind down a little bit because it can sometimes just mess around with your thinking a little bit.

And if it's one of those days where you have a cluster of them, that can confuse things a bit. My day might be a bit slower if I've got a headache. Today, I've got one

of my cluster headaches. I've actually got it now. I've got it now, and I'm working through it. I don't look for sympathy. I tell my manager, she'll ask me what's your day like, and I'll tell her what it's like, I'll be honest about it, but I've got to work through it.

CB Daniel, absence seizures, are they common?

DJ Yes, they are one of the more common types of epileptic seizures. The difficulty with absence seizures is, because of their nature, a lot of the time, it can take quite a long time to diagnose. So, even people who have other types of seizures, as well, won't necessarily know they're having absence seizures on top of those other seizures.

Again, it's one of those ones that is really difficult to diagnose and notice a lot of the time, and we've had examples of children in school, who've just been told that they're not paying attention, when actually, they're having absence seizures, and it's not been picked up.

00:08:35

CB Yes, that's actually quite worrying, isn't it? So, you're having a seizure, and then afterwards, you're being told off about that because the awareness isn't there.

DJ Yes.

CB And that creates a whole other cycle of problems for that child. What treatments exist? Are there any?

DJ Well, yes, there's medication, which for a lot of people can be very effective at controlling seizures, but for others, not so much. So, I think the latest research suggests that about 50% of people with epilepsy can have their seizures controlled when they're [talking].

CB 15?

DJ 50%.

CB 50?

DJ 50, yes. But with the right medication, it can go up to 70%. And then there are other treatments, as well, brain surgery. There's quite an exciting new type of brain surgery that's, hopefully, being launched on the NHS this year, which is MRI-guided laser surgery.

00:09:34

So, at the moment, brain surgery involves cutting out a chunk of the brain, which can be very dangerous, and there's a risk of damaging other parts of the brain, as well. I can't remember the exact numbers, but it's a very small number of people with epilepsy that are eligible for the current type of brain surgery.

With the MRI laser-guided surgery, because the laser's guided to the specific part of the brain that's causing seizures, damage to the other parts of the brain are minimised. So, hopefully, that could lead to a lot more people being eligible for that kind of surgery.

CB Is this research and the new technology funded by the government, or is it funded by charities, such as Epilepsy Action and the other ones that exist?

DJ Some of that research is. I think the MRI laser-guided surgery was undertaken by a university. I think, off the top of my head, it was King's College. Great Ormond Street have been performing it for a while. And now it's going to be rolled out in other centres across the country, through the NHS.

CB That's amazing.

DJ Yes, it's been something that's been available in America for a long time, actually, but it has taken, yes, too long, really, to be rolled out here. But still, it's very exciting.

And then, for some people, as well, the ketogenic diet is another treatment option that helps control seizures. And something else that is emerging, as well, is medicinal cannabis that has been very effective in a lot of children. Despite being legalised by the government four years ago, it's still very, very difficult to access through the NHS at the moment.

00:11:18

CB It's so frustrating for thousands and thousands of people, that it's there, it's getting access to it.

DJ Yes. And we've heard from people who have had to go through private neurologists to get prescriptions for medicinal cannabis, but that leads to costs of up to £2,000 a month.

CB Oh, my goodness gracious. Crikey. Who can afford that?

DJ Well, yes, very, very few people. Most of the people that have been able to access it are relying on crowdfunding month-to-month to be able to afford that medication. Again, during the pandemic, we saw that crowdfunding effort fall apart, as well, really. So, it's very frustrating that despite the change in the law, it's still very difficult for people to access.

CB I have heard of other people who have had other health conditions, and how this cannabis is really, really fantastic preventative, but they're buying it on the black market.

00:12:17

DJ Yes, and that's very dangerous, especially for people with epilepsy, where we know that, actually, buying it on the black market can cause more seizures, rather than

controlling seizures, like medicinal cannabis. So, there is a big difference between the two. And yes, that lack of access is forcing people to make difficult and dangerous decisions sometimes.

CB Just going back to the operation, I actually spoke to somebody on the podcast just recently, whose mother had experienced seizures. I don't think they were absence seizures, I'm not actually sure what type of seizures they were, but they were enough that they were really severely impacting her quality of life. She had an operation on her brain.

But one of the possible side effects was short-term memory loss, and she said that it completely has done that, so she can remember things from ages and ages ago, but just that short-term memory loss, it's quite significant.

DJ Yes, absolutely. It's something that it can be a side effect of epilepsy medicines, as well, but a lot of the epilepsy medicines, unfortunately, have some really severe side effects. In some cases, well, very rare cases, they can be worse than the actual condition, itself. Long-term impacts.

And then with sodium valproate, we're seeing the impact it can have on unborn children if taken during pregnancy. There's all sorts of other issues there, alongside the epilepsy itself. It's a really insidious condition sometimes.

CB Yes. Murray, can you tell me about the trial that you're participating in?

00:14:04

MG Yes. I've just come to the end of it. I've been working with a company... Working with. I've been part of a trial with a company called UNEEG, and I'm wearing a device called a subcutaneous EEG. A SubQ. And it is an EEG that you wear 24 hours a day, and it is a wire that, basically, runs 10 cm down the length of my temporal lobe. So that's where the issue is. That's where I've had the problems since I was 16.

CB And Murray is pointing, just for the podcast format, to the side of his temple.

MG At the side of my head.

CB Yes, side of his head, down to the back.

MG Side of my head. That's where I always had the problem, and I've been into hospital twice to try and capture the seizures, to try and find out a bit more about. The trial was about trying to see if your seizure diaries were accurate, that's what it was all about, and a lot of people's seizure diaries weren't.

When I was recording my seizures, I was having six seizures a day when I was 16. Through having a lot of the medications, I've had probably five different changes

over the years, I got down to, maybe, six seizures, on average, a month. Over the trial, what they were trying to do was capture seizures, and it was all about trying to predict whether, using algorithms, they could predict seizures, going forward, in the future. And by wearing this device, and again, this is what it looks like, you can see this disc on my chest.

00:15:43

CB Oh, yes.

MG That's what's underneath. Underneath my clothes. So that's got a little wire that runs up to the device.

CB It almost looks like an apple remote control, that sort of size, doesn't it?

MG Exactly. Exactly. This is the second one I've just had installed. But what they found was, over 15 months, I was correct in my recording of the ones I did capture, but I'm having up to 25 a month. Over 12 months, in a 12-month period, they captured 300 subclinical seizures, as well. So, for every one seizure I'm having, I'm having almost five of what they call an earthquake tremor seizure.

So, for me, personally, you were just talking about surgery, I can't have surgery, and any other type of surgery because of where the epilepsy is at the moment. So, for me, going forward, medication is the way for me. I've donated my data for other people, hopefully, going forward.

And in the future, with medication changes, what they'll be able to do with this data live is pass it on once a month to my neurologist. She's going to get my data, she'll be able to, with algorithms, change my medication on the fly. That's what it's going to do.

00:17:01

CB Oh, right, so that's going to eliminate the side effects that Daniel was talking about.

MG Yes. So, potentially, it could be with this data that's going out there, she could say, right, I can see things happening, so you could actually tweak your medication. At the moment, I take a bog-standard amount of medication a day, she could say can see something happening here, so could you actually up or down it as things happen.

CB That's amazing.

MG Yes, very clever.

CB You are listening to the Sunflower Conversations with Chantal. To find out more about the topics discussed in this podcast, details are in the show notes.

If you weren't taking medication, you be having significantly more absence seizures, presumably, so you've got it in the best place that you can possibly get it, and it's around, was it six a day or 20 a day?

MG With my seizures at the moment, I was having six seizures a day at the beginning. I'm now down to six a month. But, say, last month, I had no seizures, and because of that, it can catch up with you. So, already, this week, I've had five. It's so unpredictable, like I said. So, I can go a month with none, but then I can get hit with a spate of them. In one weekend a few years ago, I had 90.

00:18:22

CB Oh, my goodness me. Is it tiring?

MG I was hospitalised because of it.

CB You were hospitalised.

MG Yes. And they're only absence seizures, but they actually came out in a different way, and I could feel physical sensations. It felt like my skin was ripping apart. So, totally different, again.

CB Ooh, that's painful. Very painful. The brain is the nervous centre of our entire body, isn't it?

MG Weird. It's a very strange thing. The worst thing for me now... Like I said, I'm not scared of the epilepsy itself, and I know it's very different patient-to-patient, person-to-person, the most difficult thing for me now is the side effects, the headaches, funnily enough. It's headaches.

CB Will a paracetamol help that or not?

MG No. So, they class mine as being migraine stroke, plus the headache, so I have to take preventative tablets every single day.

DJ You're shake, rattling, and rolling, aren't you?

00:19:19

MG Yes. But I have to work with it. Like I say, it's been a long time now, and I have to work with it. So that's one of the things I very much promote is I have to live with mine, and that's where I am with it. I try to own my own condition. It's difficult. It's very difficult, but I've had it a long time now and I just have to work with it. I have to do something with it.

CB Well, I think that your approach seems to be centred around your mental health, so that kind of acceptance that this is part of me, and I have to work with it to get the best outcome. Whereas if you were denying it, refusing it, the outcome would,

potentially, be different. More different for you, particularly from a mental health point of view.

MG I can't let it rule me. I can't. But I do understand that I'm very lucky, as well, because I know people living with epilepsy that have got it a lot worse. I'm also very grateful for that, as well. Because when I found out I had... When I was diagnosed with epilepsy, when I started having the symptoms, and things happening, I actually thought I had cancer.

When I was 16 and these things were happening, I didn't know what was wrong with me because I didn't have it from birth. Because I was like, strange things happening. So, when I was diagnosed, I was happy that it was epilepsy and not something else because I didn't know what was happening.

00:20:56

CB That's quite a significant thing when you're 16, as well, isn't it?

MG Yes. I was scared. I was very scared, yes.

CB Daniel, let's talk about Epilepsy Action and let's talk about access. What complaints do Epilepsy Action receive, and what action is the charity taking?

DJ We've had complaints similar to Murray's about being turned away from venues, or people not understanding the condition, not thinking that... Because it's an invisible condition, question you saying that you're disabled when you've got epilepsy. So, similar to what Murray was saying earlier, as well, we've had people kicked out of supermarkets when they've had a seizure because people think they're drunk or acting out. So, yes, that's the things we've had reported to us.

In terms of what we're doing, always, we're trying to raise awareness of the condition. Just this week, we've launched a first aid video explaining what people can do if they see someone having a seizure. And that's one of the biggest things, really, a lot of people just don't know what to do or can't recognise people having a seizure.

It's something that's been reported to us as a barrier to employment, as well. Employers reluctant to hire people with epilepsy because they don't know what to do. They were worried about their other employees seeing someone having a seizure and the impact that could have.

00:22:32

We've worked with some employers, providing training directly. But also, launched an employer toolkit, again, just gives that first aid information, outlines what reasonable adjustments could be made for people with epilepsy, to help them find and stay in work.

CB Excuse me, sorry. That sounds great. It's just such a weird way, isn't it, as in the person who has epilepsy is going through this impact to daily life, and then on top of that, it's the worry about how am I'm being viewed when I have a seizure. And then to know that an employer is reluctant to employ me because of the impact it might have on other people who don't have epilepsy. That's a really tough pill to swallow.

DJ Yes, like you say, it's that backwards way of looking at it, not what the impact the seizure is having on the person with epilepsy, but the impact of seeing a seizure could have on other people. Yes, it's very concerning from our point of view, obviously, and the impact that it has on people with epilepsy must be horrifying. And another bit of research that we've seen recently was highlighting the link between people with epilepsy and their agoraphobia.

CB Do you know what, I was just going to say... Well, I wasn't just going to say. Earlier on, I was going to say that I can imagine that for many people, going out is a real worry.

00:24:07

DJ Yes. Just the worry of having a seizure in public and worrying that people will think you're being drunk, will not know what to do if you're having a seizure, so it is really concerning. Reading between the lines of that, that research, that's the assumption we made, that people were reluctant to go out, they feared going out in public just because of those misconceptions that are still there, unfortunately.

So many of the problems that people with epilepsy face comes from that lack of awareness, the misunderstanding, and the misconceptions. If we can knock those down one by one, then hopefully, we'll be improving peoples lives.

CB Well, yes, it's all about education and awareness, isn't it, that's why we're doing this podcast right now. So, Murray, can you talk me through some of the barriers that you face when you've been attending venues? I know that you are massively into your music, so yes, can you talk me through some of those barriers that you faced and some of the quick wins that you've advised promoters that they could adopt?

MG I've had issues. I like to challenge, sometimes, just to understand what people know or don't know about hidden disabilities. So, sometimes, I like to test the people at the venues, themselves, I ask them what do you think is wrong with me, and stuff like that. Get them to have a look at me, maybe check the lanyards, and stuff like that. So, I've done things I can spot-test.

Because I've got things, signs, on me, anything up to five signs, that could give away exactly what's wrong with me, aside from the lanyard that I've got, that we're talking about... They have bars for areas for disabled people. The lowered bar, for example, for people with physical disabilities.

00:26:09

I could be at risk of having a seizure within 50 m. So, a lot of the time, when there's a queue, you could go to that bar to just get a drink, get a soft drink. And once, I stood there for ten minutes, waiting to get served, and the bar had an empty drinks bin in the front of it, so that could have been used by someone in a wheelchair.

When I went to stand there, the queue next to me, everyone was standing there looking at me, and I was accused of queue jumping because I was standing. I had to get the bar manager's attention to actually come over, they said can I help you, the queue's over there, and I said, excuse me... I had to explain I had a disability, and the reason I was using this queue was because I had a disability, as well. So, there was that example.

Just another quick one was I always try to book seats on the end of an aisle because there has been incidents in the past, where I have actually had a tonic-clonic seizure. Three times in my life.

So, I tend not to sit in the middle of a block because if I have a tonic clonic, I could injure a patron, and that hasn't always been the case. If I have a seizure, even if it's just an absence, I have left a venue. With my wife, we would just leave so we don't interrupt anyone else's night. That hasn't always happened.

00:27:41

So, it's trying to get the venues to understand why people with epilepsy need what they need. They also need those special arrangements set up to make sure they enjoy their night, and also, don't spoil it for other people if something should happen. It's not always just about the person with the condition, it's making sure they get what they need so it doesn't interrupt the performance, as well.

CB Yes, it's supporting everybody.

MG So, I would advise them to make sure their access lines are accessible. One other thing, as well, I've waited up to 45 minutes for their access lines, for them to answer the phone, and be cut off. A lot of them have moved now, since the COVID, since the pandemic, they've really cut down on their services, and they need to bring them back up to speed. They're terrible.

CB But it's not like tickets are cheap to go to events, is it?

MG No. You pay the same price. You pay the same price as everyone else. I've actually joined an advisory group, and hopefully, get some focus groups back in place. Do you know what, some of the smaller places, the theatres, are absolutely fantastic.

We've got some really, really good places out there. It's not all bad, there's some fantastic places out there that some of the bigger venues can take some wins off of. So, it's not all negative, there's some really, really good places. So, yes.

CB Well, you must feel very happy in the fact that you are not letting your epilepsy define you and prevent you from enjoying the things that you enjoy.

00:29:16

MG Not at all.

CB And you can use your experiences to educate.

MG Always been my hobby. It'll always be my hobby. Whenever I go anywhere, there's some great door people out there, as well, some great staff, and wherever I can, I try to educate. We went to a nightclub recently. The place was fantastic, and they had a disabled toilet, they tried their best to get it right.

I let the manager know that the place was great. Just said you're, potentially, missing a few things in that toilet. They changed it within a week and now it's up to standard. It's not to pick on them and do things like that, but I said you've tried to do the right things, but it wasn't about epilepsy. I said something doesn't look right, and we actually worked together, and we made sure they got in touch with a contractor. Now it's completely to spec.

CB Why do you wear the sunflower?

MG I wear the sunflower so that people can see the unseen. It's that thing of people not thinking that I'm drunk if I have a seizure. And also, it's so they definitely know that there is something wrong with me that... It's not wrong. So that they know that I've got something else happening, and I back that up with my other lanyard to say, double, on top of that, just to make sure, that I have got epilepsy.

00:30:38

So, if you do want to come and help me, it's just to let you know it's not a heart attack. It's just to make sure if you do want to help me, it's definitely that, so that you do the right thing, in terms of first aid, for instance.

So, yes, it's a really good cause. Just to double that up, as well, I've got another one. I've got two sunflowers.

CB Sunflower wristband..

MG Yes. It's to promote you

CB Where do you wear them?

MG I wear them everywhere. I've got it on for this podcast, but as soon as I leave the front door, I wear them everywhere. It's good promotion. I wear them at the airport, as well. I wear them at the airport. It's something I heavily promote. It's a good thing to have.

CB So, Daniel, what support does Epilepsy Action offer to people who contact you?

DJ We've got our Epilepsy Action Helpline that people can contact by phone or email. So, the phone number, I'll just give a quick shout out. . And we have some great

trained staff on there that are able to offer advice on all sorts of issues, from access issues, welfare issues, and just advice and support. Especially for people who are newly diagnosed, it's a minefield.

00:31:58

A lot of the time, people don't get the information they need from the consultants or the doctors when they've first been diagnosed, and so, we're here to fill those gaps, as well.

And yes, from my point of view, as well, campaigning on issues like trying to improve the employment rate for people with epilepsy. Addressing the issues that people have with the welfare system, and things like that.

CB So, you've got the telephone number, we'll include in the show notes, and we'll also put a link to your website, as well, so people can get in touch. So, this brings me onto my final question, and, Murray, it's to you. Do you have any advice for anyone who experiences seizures and is worried?

MG I would say if you're having seizures and you're concerned, go straight to the doctor, get yourself referred to a neurologist, a consultant, and get yourself on that road to help. That would be my very first thing. Don't wait around, you could find yourself in my situation, and you could be crossing roads, you could be walking off a train platform.

That's the worst thing that could happen, so get yourself professional help and get yourself talking to a charity like Epilepsy Action. They've got a lot they can offer people. So, talk to the professionals and talk to the charities, definitely. And talk to your family and your friends.

00:33:21

CB Thank you, that is sound advice. So, thank you, both, for that, joining me today, it's been a fascinating conversation and I've really enjoyed it.

DJ Thanks for having us.

CB If you are interested in any of the advice discussed in this podcast, please, follow up with your GP or healthcare practitioner.

VO If you'd like to share your Sunflower story or conversation, please, email conversations@hiddendisabilitiesstore.com. Find out more about us or listen to this recording again by checking out our Insights page, at hiddendisabilitiesstore.com.

You can also find us on Facebook, Instagram, Twitter, YouTube, and LinkedIn. Please help. Have patience. And show kindness to others. And join us again, soon. Making the invisible visible with the Hidden Disabilities Sunflower.

00:34:27