

**Eating Safely:**

*Owen's Law - Telling the server isn't enough? - Episode 1*

**Claire McGuigan and Emma Kocher:**

CLAIRE MCGUIGAN: Hello and welcome to our Eating Safely podcast, where we are discussing Owen's Law and why telling the server isn't enough. I'm your host, Claire McGuigan. And today, we're going to be talking about food allergies, an issue that touches millions of people and one that I know many of you listening care deeply about.

So if you are someone with food allergies or someone who works in a barista bar or in a restaurant or a chef or even someone who's involved in health, in regulation, or in policy, well, then this podcast is for you.

This is very much a conversation that we want you to be part of. And so as you're listening here on podcast, if a question comes to mind, if something resonates in our discussion with you, or if you feel like you want to share your own experience, please do leave a comment.

It would be wonderful to hear from you, and adding your thoughts and experiences to this conversation may really help someone else. Now, before we begin, I want to tell you just a little bit about myself and why I'm interested in food allergies. I'm a nurse, educator, and researcher at the Open University, and my interest in food allergies developed over 15 years ago when my daughter was diagnosed with multiple food allergies.

And like so many families, we taught ourselves how to stay safe, and we have lived with daily vigilance ever since. The constant reading of labels, which will be familiar to lots of people who have food allergies and even lots of chefs who cater for them, and the extra planning that goes into keeping her safe.

We, like other allergy families, hold a quiet hope that today and every day will be a safe day. But we can't do that on our own, and that's why these conversations are so important.

The more I listen to people's stories of how they live with food allergies and the challenges they face at school, the challenges they face at work, going off to play sport, and going out socially to eat out of home and dating and all aspects of life, it is clear that the system that we all live in, and we all take for granted and all our social freedoms, they are not built with safety in mind.

And that has to change. And that is why this conversation is important. Stories are so powerful for change, and they help us understand what is going on, what it's like to live with a food allergy. And they also let us understand what could be done differently.

And by telling stories and letting other people hear those experiences, through that conversation, we are appealing to others to reach out and help. This is why this conversation matters so much.

It matters to me personally but to the families I support and also, hopefully, to you. And today, we're going to hear one of the powerful personal stories that brings all of this into focus. But before we do, let me give you some interesting facts to help set the scene so you can truly understand the importance and the scale of what we're talking about today.

Food allergy is not a choice, and it's certainly not a lifestyle trend. It's a serious medical condition, which affects the immune system and for which currently there is no cure. And for many people, it can be life-threatening.

And this, I suppose, is one of the most important facts that I think that most people in the public certainly don't realize, is the seriousness of food allergy. This medical condition affects millions of people across the world, and in the UK, over 2 million people are affected by it.

It is growing as one of the largest global health concerns across the world, as the numbers of people diagnosed continue to rise and with Australia having the highest incidence. When we speak to people, we mention the word "food allergy," most people automatically associated with nut allergy when they hear those words.

But research shows a very different picture. The research tells us that milk, eggs, and peanuts are among the most common allergens worldwide, and in some regions, they cause more reactions than nuts alone. Isn't that an interesting fact? Did you know that? Did you know that cow's milk and eggs are one of the top food allergens? So keep listening to you hear a little bit more about food allergies.

In the UK, the most common food allergies that we have are cow's milk, eggs, peanuts, tree nuts, and seafood. And cow's milk is an interesting one because, in particular, it's a major cause of severe reactions in children.

Yet, public understanding of what food allergies are remains very limited. And it's this lack of awareness that I think adds to the risks that families face every day. So hearing these facts, it raises an important question. Do you think it is time for a public health campaign to help the public understand what food allergies are, what their risks are, how we can help each other better?

Think about that as we go through the discussion. And if you do, have any thoughts on that, pop your thoughts into the comments. So now, we come to the heart of today's conversation. I'm truly delighted to welcome Emma Kocher to today's podcast.

Emma, thank you so much for joining us. Your commitment to improving safety for people with food allergies has had a remarkable impact across the UK so far, and I know your campaign continues. I'm genuinely honored to have you here with us today. So Emma, would you like to begin by introducing yourself and sharing a little bit about your interest in food allergies.

EMMA KOCHER: Hi, I'm Emma Kocher. I am co-founder of Owen's Law campaign along with my dad. We started the campaign in April 21 after we lost my little brother to anaphylaxis in 2017. I'm 16 years older than Owen. So although his sister, I did play quite a significant part in Owen's upbringing and keeping him safe from allergens, especially when eating out.

Thank you, Emma. And thank you for sharing that with us. I know you're working hard to make change to the law in the UK. But before we get into that, I want us to begin with inviting our listeners to learn through personal story, what living with a food allergy looks like.

Sharing people's experiences brings food allergies to life in a very powerful way by letting others see exactly what the impact of that is on a daily basis. And the stories of how people cope and live with food allergy make this often life-threatening medical condition, I suppose, more visible, and we need to know its impact so that we can help make things better for those people who live with food allergy.

And while, yes, we have lots of statistics, and they're very useful, but food allergy is not just a statistic. It is a serious medical condition that shapes and informs everyday life for millions of people. And yet, many people know very little about it.

And I suppose I know for our listeners that what's important for them at this stage would be that your family's story, it really does bring that reality of a food allergy into focus in a way that numbers and statistics alone never can.

So Emma, I'd like to invite you to take us a little bit deeper. Could you tell us more about Owen, what he was like, what life looked like growing up together, and how that you navigated that whole world with his food allergies.

And if you feel comfortable, I suppose, because I know this is difficult for you, could you tell us a little bit about how you lived with someone with a food allergy and how your family managed? And I suppose if you're comfortable with it, if you could tell us a little bit about how you've lived with something that no family should ever have had to face, and losing a loved one to anaphylaxis.

Yeah, thank you, Claire. So as I said earlier, I'm 16 years older than Owen. So although we're brother and sister, I did have quite a sort of significant role in his upbringing and also was very aware of how much effort our mom, in particular, was putting in to keeping him safe.

So we first started noticing his allergies right from the point when he was weaning, although in fact before that, when mom was breastfeeding him as a very small baby, he developed terrible eczema. And so mom had to control her diet and cut out dairy and wheat, gluten to try and prevent his eczema getting bad.

And then as soon as he started weaning, he started having asthma attacks. He started having bad tummy upsets with vomiting and diarrhea, and his eczema got much, much worse to the point where it cracked and was bleeding and became infected. It was incredibly painful. And that then continued.

He had asthma attacks as well fairly regularly and eventually was diagnosed with allergies to over 20 allergens. And this is allergies that cause a huge immune response, not just might have made him feel a bit uncomfortable. These were life-threatening substances that could kill him. And obviously, with over 20 allergens, this was something that had to be very, very closely regulated by our mom. So his diet was obviously immaculate. Every meal was prepared fresh. He couldn't eat any of the school food that was prepared for him because of potential cross-contamination.

So mom would prepare a meal every single day for him. He was also-- because his diet was so restricted, he was very skinny, and he was quite small. So mom was very keen to try and get as much sort of high-calorie food into him as possible. And so these foods, these meals were often a roast dinner that had to be heated up by the kitchen at school.

Similarly, when we went out, it was a similar story. Mom would always prepare food to take with us because she just couldn't risk anything going wrong in a restaurant. Going to school-- going to friends' parties, just going anywhere without her was a constant worry, and this paranoia that something he might accidentally eat something, or someone's parent might not fully understand the severity of his allergies and what could happen if something accidentally was eaten.

So it was a kind of-- it was a very closely military run operation, keeping Owen safe. He had multiple reactions and hospitalizations throughout his life. However, these were generally to do with asthma.

Now, we've been told since that asthma and food allergies, combined together, is something that is very, very dangerous, you're kind of playing Russian roulette because you've got internal allergies, effectively ones that you consume, but also you've got airborne allergies, which can cause a similar effect.

Now, when we ate out, even if Owen wasn't eating the food in the restaurant, if, for example, we were in a pizza restaurant, and there was flour in the air, wheat flour in the air, Owen would trigger an asthma attack with that.

Or, I remember one time going to a coffee shop, and they were steaming milk, and Owen started having an asthma attack because there were milk droplets in the air. So his allergies were so profound that it really, really limited his life.

And obviously, the reactions that he had, the vomiting, the diarrhea, the eczema, that was so painful. At one point he had eczema on his eye on the inside of his eyelid because of, again, airborne allergy allergens like pollen or maybe dust mites.

And it meant that he couldn't open his eye properly and was in excruciating pain. And the fact that he bought all of this but was still so cheerful, so happy, a real prankster. He was the class clown, and he got away with murder at school because he was so jolly and so happy and cheeky and sweet and that then as he turned into a teenager, he became this sort of jovial prankster, mucking around with his friends, always in really good humor.

And when I had children, he was only nine when I had my son and then subsequently my two daughters. And he was just so close to them and just the most amazing uncle, just really sappy.

And even as a teenage boy, you think might be a bit standoffish with young kids, but oh, he just wanted to cuddle them the whole time and then obviously a good amount of rough and tumble and playing with them despite the fact that he was in a constant level of pain and discomfort somewhere in his body.

And then on the day he died, everything was still like a normal day. We were celebrating his 18th birthday. The rest of the family had only seen him a week or so before, celebrating at dad's house.

It was dad's 60th, the day before Owen-- the day after Owen's birthday, and we were all celebrating together. And then the following week, all the boys of the family. So our other brother Daniel, Owen, my husband Richard, and my son Gulliver, and Owen's girlfriend Martha tagged along as well.

They all went to the O2 for the Star Wars exhibition. So they spent the morning completely geeking out, playing with lightsabers, creating alien versions of themselves, having just the best time. And then they needed to look for somewhere for lunch.

They decided against one place because they knew there was peanut oil used to fry some of the chips. So they ended up going to Byron Burger because that seemed like the safest option. So again, constantly trying to find somewhere that would fit Owen's needs.

When they got to Byron burger, they declared Owen's allegiance to the server. They had a detailed discussion about what would be a safe meal for him to eat, and they decided on having chicken breast without any kind of bun or anything, with fries and salad but no dressing. So it was a very plain meal, and this had been tailored for Owen's needs, having declared his allergens.

That meal came, and he only ate a few bites and started feeling strange. So he only stopped-- so he stopped eating after just a few bites. He traveled to the South bank, then for the second part of his birthday, which was going on the London Eye with his girlfriend.

But he had to keep stopping on the way because his breathing was getting worse and worse, and he was puffing on his inhaler the whole time. He got there after about 20 minutes. And by the time he got to the foot of the London Eye, he collapsed.

He couldn't breathe, and a passing army medic started CPR within a minute or two of him collapsing, and an ambulance arrived after seven minutes. And they worked on him for quite a while, and they took him straight to the hospital.

But after 45 minutes, they had to stop their resuscitation attempts because there was no chance of him coming back. And it turned out, subsequently, we found out that there had been buttermilk in the chicken. It had been marinated in buttermilk. So despite declaring his allergies, something was served to him, which killed him. As you can imagine, this has been really catastrophic for our family. Sorry.

CLAIRE MCGUIGAN: Are you OK? Just take a moment, Emma. Are you OK? It's really lovely. It's really lovely for you sharing the lovely insight into looking back at the scale of his allergens and how they affected him, but also those beautiful memories you've shared with us, his lovely personality and his presence.

And I can hear in your voice, how teary your experiences together and your memories together are nice. But I can't imagine for one minute how impactful it has been for him not to be here with you. And so just take a moment.

EMMA KOCHER: Yeah, I think that's the thing, is that there was so much love within our family. There was so much joy. And for all of us, we miss that so much. We miss the laughter. We miss the pranks. We miss the music.

He was constantly playing a guitar, or he would always bring a ukulele or something along to family gatherings. He wasn't an amazing musician, but he loved music. And he would talk at us at length about some latest band that he'd discovered. We miss that so much.

And anyone who's lost someone young will have the same thing. You miss them, but you also miss the things that could have been. And I kind look at my children now have missed out on so much uncles, so much role modeling, so much love. And that is something that I grieve for my children and for the rest of us.

And to think that this could have been prevented so easily by better communication, whether that was through the different steps in a kitchen, through the server declaring it to the chef, the chef looking at the ingredients, it could have been prevented so easily, and Owen could still be here.

And advances in medications and things like that, his life with his eczema and all of his asthma and things like that, medical advances could have actually made his life, since then, more comfortable.

Obviously, allergies are never going to be or probably, in our lifetime, going to be cured as such. But there are already medical advances to make life easier for allergy sufferers. And I just think he's missed out on so much. We've missed out on so much.

CLAIRE MCGUIGAN: Oh, Emma, I'm lost for words, really. Listen to you. I can hear the love that surrounded Owen. And I get a real sense of loss and of the loss that you and your family are living with every day. And I'm so sorry. I know this is difficult for you to share with us. So thank you for trusting me and your listeners with your story.

Emma, you have shared a deeply moving and personal story with us, which is heartbreaking. And by sharing it with us, it really does help us understand what is truly at stake.

And I suppose, for our listeners who are maybe not so familiar with your campaign but for allergy families who are, it really does highlight why your campaign and other campaigns, and these conversations are so important to raising the profile of food allergies.

It is a very moving story, and I suppose as a mom of a child with food allergies, it's heartbreaking. It really is impossible to hear what your family has lived through and not appreciate the reality of what people with food allergies face every single day.

They are navigating a world that was not built to keep them safe from coffee shops and restaurants to fast food counters for eating on planes and trains and at schools and workplaces and even in hospitals.

The very ordinary everyday environments, they become obstacle courses for people that have food allergies and where one gap in communication or one missing label can actually have life-threatening consequences.

And I think your story is very powerful, and it has put that message across. I think for our listeners, whether you're a parent or a carer looking after somebody with food allergies, or if you're someone working in hospitality, I think you couldn't but be moved by Emma's story.

We'd love to hear what resonated with you, and we'd love-- your voice does matter to us, and we'd love to hear your experiences. They might be something that other people need to hear as well, so it'd be important just if you would like to put your comments at the bottom of the podcast.

So today, we actually focused on a very personal side of food allergy with the emotional toll of it, the human cost, and the ongoing heartbreak of knowing that even when someone does do everything right, the system around them can still feel.

And that is an issue then that we're going to look at in the second part of this Eating Safely podcast. On our next episode, we are going to move from the personal story to talk about how hospitality systems need to change.

We'll be joined by a full panel of experts who each bring something interesting and unique and vital to this conversation. So in the meantime, let's keep the conversation going because I think what's important to remember is that the truth of what has happened to Owen is that he did everything that he was supposed to do.

He declared his allergies to the server. He asked the right questions. And I suppose, as an allergy mom, school your child in doing that their whole life. So you do what you can to prepare them.

And at the interface then, when he was asking genuinely for support from the server, the server believed that the information they gave them was correct. So the problem wasn't own. The problem was the system around him, which that failed him, which really does prove that asking the server isn't enough.

So in part 2, we will look at more detail at how the system can and must change. We'll discuss things, like staff training, the need for allergies to be written clearly on menus so customers can make the right choices, and right through to whose responsibility is it and the law and legal accountability.

This conversation is not about blame. It's about trying to get in underneath some of the issues and some of the culture and practices that are there. And in the next part, you will hear about how change is happening, although more still needs to be done.

So these podcasts are really about getting people thinking, getting conversations going, and getting ideas generated about how businesses can design processes that actually are focused on safety and protect lives.

So if today's conversation opened your eyes or brought back maybe a frightening moment or simply made you think differently, please share your comments. Big or small, your story might help someone else feel less alone. So join us for part 2 of the Eating Safely podcast. And in the meantime, if you want to learn more about Owen's Law, you can go to [www.owens-law.co.uk](http://www.owens-law.co.uk). Thank you.