

Congenital anosmia and visual impairment with Claire-Louise Pitman

Speaker Key:

VO	Voiceover
CB	Chantal Boyle
CP	Claire-Louise Pitman

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

CB Welcome to The Sunflower Conversations. I'm Chantal and joining me today is Claire-Louise Pitman. Claire-Louise has congenital anosmia and is severely visually impaired. So, how are you doing, Claire-Louise, today?

CP I'm good. Are you okay?

CB Yes, I'm very well, thank you very much. So, I'm really interested to learn more about congenital anosmia. Can you tell me more?

CP So, basically, it's just a fancy word for an inability not to smell. Congenital anosmia is lifelong. You've never had it and never will have it. It can be passed through genetics, and sometimes you don't know how it's occurred.

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CB And so, basically, it's your sense of smell?

CP Yes.

CB Simply put. So, I would imagine that can bring up lots of barriers. So, was there a defining moment, then, when your parents or you realised that you had no sense of smell?

CP I think it was when I was in Year 7. I couldn't understand why people were leaning into their food and sniffing it. I was just, what are you doing? And in the ladies' changing rooms and people putting deodorant on, I couldn't understand the purpose of it. And they'd be like, of course it's to get rid of odours, because your armpits smell. And I was like, do they? And then I started questioning myself. Do I actually can't smell? And then I thought, yes, I don't think I can.

So then, I told my parents, and it was almost like I had to convince them that I couldn't smell. And they were giving me things to sniff, and I just sat there puzzled. And then they sort of agreed with me in the end.

CB It's interesting, isn't it? I don't know. I'm thinking about your parents and you having to convince them that you couldn't smell, and the fact that they hadn't picked up on that. You said you were aged seven?

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CP Year 7.

CB Oh, Year 7, so you were in secondary school. So, you were about 11 years of age at that point, aren't you?

CP Yes.

CB And prior to that, it hadn't been noticed. Because one of the things it's making me think about immediately is the smell of cooking, or the smell of chocolate, and things like that, when we talk about the aromas. Or, for example, this morning I have made a spaghetti Bolognese, and my son was complaining to me because he said his school uniform was really going to smell of onions. But in your household, your parents just probably thought you were really easy-going.

CP Yes.

CB Picking up on what I was talking about with the spaghetti Bolognese, has your sense of smell had an impact on your sense of taste? What was eating like for you when you were growing up?

CP When I was growing up, everything was normal, so I thought everything tasted the way it should and is. But then when I understood that I was anosmic, I noticed things don't taste the same for me as they do to other people. Working out meals that they're too soft just makes me feel sick.

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CB So, texture is very important for you.

CP Yes. So then, I took control of what I actually wanted to eat rather than what was given or offered.

CB So, up until that point, were mealtimes an issue at home with your family? Would you sit down and eat everything that they put in front of you, or did you have an opinion on it? So, for example, if something was a bit soft and it made you feel nauseous, did that cause an issue? Did you parents think you were being picky?

CP I think they think I'm a bit picky, anyway.

CB Just generally, in life?

CP Yes.

CB And does everything taste the same? So, for example, if you were to eat... Are you vegetarian?

CP No.

CB So, if you were to eat a sausage and you were to eat a tomato, is it the same flavour, or is it different?

CP Different.

CB So, you can detect different flavours, but it's not necessarily the actual flavour?

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CP Yes.

CB And so, on a day-to-day basis, how has this affected your life, not being able to smell?

CP I suppose there's always a subconscious thing back in my mind that every day I've got this condition, and I need to be aware and alert. I still forget to open windows if I'm cooking, because I'm not very good at seeing the smoke, nor can I really smell the smoke. I'm always checking alarms in this house.

CB So, when you're talking about having to be alert, what specifically do you need to be alert to?

CP Just the general situations. So, I'm cooking, make sure the windows are open, the alarms are working.

CB And is it alert to danger?

CP Yes, pretty much.

CB So, smelling smoke?

CP Yes.

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CB If something's been left on a pan and it's burning, if you were in another room, I would be able to smell that, but you wouldn't know until you got into the kitchen and stood right in front of the hob. You mentioned that your sight is impaired, so that's another one of the key senses, isn't it? Can you just tell me how you were telling me before about the challenges that you face with, have some food, is food okay to eat?

CP Making sure things are in date and edible in the fridge, and things like that. Because with milk, to me, milk tastes sour anyway on its own. So, when it's out of date, I still think it's all right, and I've had out-of-date milk. Luckily, I've been all right, for some reason. So, yes, making sure it's in date, and even if it is and it still looks a bit funny. But sometimes the dates are too small, so I usually put my own labels so I can see them.

CB That's a good point, actually, about the accessibility of the packaging. It's been a big thing that the RNIB are working on all the time, because it's so small. It's really difficult. And if you've got an allergy or something, trying to read the ingredients is very difficult.

CP Yes, it is.

CB And then added, if it's something... Because very often, they said, oh well, the dates is just the dates, it's okay, you've got a few more days on top of that. However, the way that I would know is to smell the item. I visually look, has it got mould on it? But often, before the mould arrives, there's a smell, which would indicate to me that this is not safe to eat. You don't have that, do you?

CP No.

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- CB So, that's at home. How has it affected you socially?
- CP I suppose a bit of paranoia, if I smell myself and I'm clean. If we go out to eat, I try and get what everybody else is getting, because it's just easier that way. But then if I don't enjoy it, I try and hide it. I don't know why. Yes, and if I don't enjoy it, I won't finish it, and then I feel bad I'm not joining in with the whole event.
- CB Yes, the experience, because eating is quite a social act, isn't it? And an enjoyment of your meal is crucial to that, otherwise you may as well just go out and have a glass of wine, or something, or a glass of water. So, enjoying your food is a key element of that. So, do you feel that you do a lot of this pleasing others? Is that part of your character, do you think, or is it a result of you being visually impaired and your anosmia?
- CP A result, I think.
- CB Because you are able to taste something, if you were to choose something to eat, what would you go for? Like, if it was just totally your choice, nobody else cares, what would you go for?
- CP Chicken curry.
- CB Chicken curry. So, something with a lot of spice, then, you can get a bit more of a flavour from that, and the texture of the chicken is something to chew into.
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- CP Yes, exactly.
- CB You are listening to The Sunflower Conversations with Chantal. To learn more about The Sunflower, visit our website. Details are in the show notes.
- So, when you discovered that you had anosmia, did it take a long time for them to give you a formal diagnosis of that?
- CP I don't even know if I've been probably diagnosed. When I went to my last, I suppose, nose appointment, the doctor said, we thought you might not be able to smell. I was a bit taken aback by that. I said, excuse me? Because they didn't tell my parents either, so they were a bit confused.
- CB Why are you seeing the doctor for your nose?
- CP A check-up from my operation that they did on my nose.
- CB So, the operation was, you had to have a titanium plate fitted, didn't you, when you were a tiny baby. Can you tell us a little bit more about that?
- CP Well, basically, my skull wasn't developed properly in the womb, which was called nasal encephalocele. So, they didn't know about this till I obviously came out the womb, wasn't breathing properly, and my brain was coming down my nose. They had to act fast, and I went to four different hospitals, I think. So, they had to pop my brain back up with a titanium plate. By doing that, they said they went too far into my nose and damaged the fibres, which also, I think, brought on the lack of vision.

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And then during the operation they had to cut my skin off over my skull. That was called a corneal incision. With all the bandages and whatever they had to use, they then discovered I was allergic to the sticky stuff on that, so now I'm allergic to plasters. So, I went bright red. I was itching, apparently. I had some seizures, which thankfully now I don't have.

CB You went through quite a lot as a new-born baby. Your parents must have been so worried.

CP Yes, they were.

CB So, they saved you life, this operation, but unfortunately there has been some damage which was sustained as a result of what they had to do, like a major operation. I can't even imagine what that is like doing that to a new-born baby. So, therefore, that's why the doctor said to you, we thought you might have that, but just didn't think to mention it to anybody.

CP Yes.

CB That would've been helpful, wouldn't it?

CP It would, yes.

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CB Just going back, so we were talking about how it has affected you socially. So, when you were in Year 7 and then you came to the realisation, I can't smell, did it have any effects? Do you feel like your character changed then? Because before, you didn't realise. Then, once you know, did your character change and do you feel that made a difference to your experience at secondary school?

CP Not really. Sure, I suppose it did in the sense of personal hygiene and trying to make sure I smell normal like everybody else, and then not overdo it and put too much body spray on.

CB Because we're very self-conscious, aren't we, when we're in our teens. Year 7, that's when everything goes a little bit haywire for all young people. Do I fit it in, how I look? Do I smell? Because body odour can really become quite pungent at that age. And if you're not aware of it, somebody makes a comment and you haven't realised, and it's incredibly difficult, I would've thought.

CP Yes, it was.

CB Were your friends kind to you about it?

CP I don't know. Because they didn't know, I can't really...

CB Oh, you didn't tell them. You didn't tell anyone?

CP No, not really, because I didn't know who to tell and how to go about it.

CB So, you contacted us because you wanted people to learn more about anosmia. How old are you now?

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CP 23.

CB So, when did you start feeling like, actually, I want to talk about this, I want people to understand? When did that change occur?

CP I think college, because I did my final major project on it, and people were surprised and thought, I didn't realise you couldn't smell. And I thought, from my point of view it's quite obvious, but maybe it actually isn't.

CB So, do you get your mum to help you? When you get ready in the morning, are you like, am I an okay level from fragrance?

CP Yes.

CB Well, that's great that you did your project on it, and then presumably that's then given you the confidence to then talk about it more and contact us to do this podcast to raise awareness of it.

CP Yes, it did.

CB So, one of the symptoms of COVID was loss in smell, wasn't it? And in some cases, people having COVID, whilst they actually had COVID, I know that things smelled differently. So, for example, a friend of mine, everything smelled like a candle and tasted like a candle. When she was eating things, it tasted like a candle.

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But there are treatments, I believe, such as smell training for COVID patients. Because of how you think that your anosmia was caused because of the operation, and maybe some damage being done, are there any treatments that you can try or have tried?

CP Yes, from the previous meeting I just spoke about, he did say there's this operation we could give you that might give you a small amount of scent to you, or nothing. And I thought, it's not worth it for me personally, then. I'd rather have it 100% and it actually work, rather than go in there and it might not work at all.

CB Because it's quite a big operation, I would've thought.

CP Yes, it probably would be.

CB So, you have just decided to live with it as part of who you are.

CP Until they come up with something better and more definite, then, yes, it is what it is.

CB Yes, you want some certainty before you undergo a major operation, which is completely understandable. So, where do you go? Where did you turn to for help and support? Or have you found an organisation that's been able to support you?

CP I suppose when I first discovered, I googled it as normal people would and started reading other people's stories. There was one lady who forgot about a candle that she left on in her flat, and luckily, she got out when the flat caught fire. And I thought, is this going to be my future? And then I found Facebook groups of anosmia, because there's different types of anosmia. You choose what group you fit in.

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But as you were saying from the COVID, people were joining the groups, saying they couldn't smell. But that was because of COVID, so they were going to get it back, so that made me quite annoyed. So, eventually, I was just leaving them one by one, because I couldn't take it. They get their scent back, whereas us people, we've got to live with this for the rest of our lives.

Then I found the Fifth Sense charity, and they liked one of the images from my final major project where somebody's asleep in front of gas tanks, so they used that for their [inaudible]. I can't remember the exact organisation, but some sort of gas alarm company.

CB I'd love to see the picture. You have to send it over, and we can share it.

CP I've never seen somebody who can't smell face to face. It's always online.

CB Would you like to meet up with people who have got the same anosmia as you, and have that connection? Would you feel that it would be of support to you?

CP Yes, I think it would, because you would bounce off each other and probably have the same stories related, yes.

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CB I remember when we spoke before, you were saying that people still now give you things and say, but can't you smell this?

CP Yes. I don't understand that. And then they say, so, you've never been able to smell? Like it's a question. I'm like, yes, I've never been able to smell, and even if you do give me something to smell, it's not going to happen.

CB How does it make you feel when people do that?

CP I don't know. I feel very awkward and think, are they really not listening to what I've just said? And then I pretend to sniff it, which probably doesn't help in the long run, and then I pretend to act, yes, horrible.

CB So, it's forcing you into this position that you're extremely uncomfortable with. You just want to be listened to and heard.

CP Yes.

CB So, you mentioned about this striking image, I've got it visualised in my head, of somebody laying down next to gas bottles. Did you do this with your camera-less photography?

CP So, I'll try and keep this simple. Camera-less photography is any process or technique that doesn't involve a typical camera. So, it's about using light-sensitive materials, or a flatbed scanner, or a scanner on a printer.

CB How do you find that? Because you have a visual impairment. What is your vision like?

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CP I suppose I'm good with close-up things. I can thread a needle. I'm not very good

at peripheral vision. So, somebody comes up to me from the side, I haven't got a clue they're there. I suppose I do have long vision, but the further along it gets, it gets blurrier and less detailed. I'm not very good at depths of steps, or perception of how far things are. I think they're either further away or closer than they actually are.

CB Do you use any aides?

CP I have a white cane, but it's just a standing holding cane to let people know.

CB So, that combined with not being able to smell presumably adds to a bit of anxiety when you're out and about. Like you say, the dangers, because you've got the danger of, am I judging this step correctly, am I going to fall, with the added fear of not being able to be alert to danger from your sense of smell. It sounds quite tough.

CP Yes, it is.

CB Well, I think it's really wonderful that you've shared your story with us today to highlight what the condition is. And do you have any advice for anyone who has anosmia and is feeling isolated?

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CP I suppose I would say research is important, and proper facts that you know are true. There are cooking books for anosmic people that I haven't yet tried, but I would presume are good. I suppose I would advise if you're not enjoying your meal and you're not going to finish it, it's not worth putting yourself through those feelings, and you should just leave it. And maybe also, I suppose, the cheesy you're not alone, and try and find people that are like you.

CB And that's lovely advice. And you should get that book, the cookbook, and have a go. Get back in touch with us and let us know how it went, and if you had any meals that you enjoyed.

CP Yes.

CB Well, thank you very much, Claire-Louise. It's been very enlightening. And I wish you all the best with your camera-less photography course and your cooking from the anosmic cookbook.

CP Thank you for having me.

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

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