

Eating Disorder, Autism, ADHD with Adam Fare

Speaker Key:

CB Chantal Boyle

PS Paul Shriever

AF Adam Fare

VO Voice Over

VO

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

00:00:19

CB

Before we start the interview, I wanted to issue a content warning. Today's topic is eating disorders, and throughout the podcast, our guests will talk about their lived experiences as well as signposting to charities for support. Please visit your healthcare provider if you are concerned about any issues relating to this topic.

Welcome to the Sunflower Conversations. I'm your host, Chantal, and joining me is my colleague, Paul. Welcome, Paul. How are you?

PS

Very well, Chantal. Lovely to see you.

CB

Our guest is Adam Fare, who is neurodivergent. Adam has a stoma as a result of his severe intestinal issues and a prolapsed bowel, as well as musculoskeletal syndrome, all of which leave him with chronic pain and fatigue. Adam joins us today to share his lived experience of eating disorders. So that's what we're going to be focusing on today when we have our chat, and I think it's going to be a very interesting topic to cover. So thanks, Adam, for joining us.

00:01:22

AF

Oh, thanks so much.

CB

Yes, that's brilliant. And Paul, how have you been?

PS

I'm all right, thanks. Yes, it's very cold here, and it's January, so I'm spending a lot of time in my little corner, working away. But I'm all right. I've got my heater on underneath my desk, so I'm fine. Yes, we've been busy, and life goes on, doesn't it?

CB

It does. I think we're all sitting here with lots and lots of layers on.

PS

Yes. Yes, absolutely.

CB

I've got my fingerless gloves on that I got for Christmas.

PS

Yes.

CB

25 layers. I can see that Adam's layered up as well.

AF

Yes, I'm layered up in my... I've got a little home office which is... The window gets the sun all morning, so it's quite nice and warm in here.

PS

Lovely.

CB

That is good. That's really helpful. Saves a little bit on the energy heating.

00:02:10

AF

Yes.

CB

That's for sure. So despite Adam's many health conditions, he is very busy. He works for a company called EKFB and is Co-Chair of their Ability Network. He's also busy, outside of work, delivering public speaking about his own lived experience of disability.

There are many myths surrounding eating disorders, one of which is that it doesn't affect men. However, according to the charity Beat UK, of the estimated 1.25 million people in the UK who have an eating disorder, 25% of them will be men. Adam, what age did your eating disorder begin to develop, and do you remember why it started?

AF

Yes. So my eating disorder started to develop when I was 11, going on 12, when I transitioned to secondary school. It came at a vulnerable time for me for a couple of reasons. So firstly, I went on holiday during the summer after my primary school year, went on family holiday, and I picked up some sort of food virus which made my bowels quite nasty, let's put it that way, my digestive system quite nasty.

Didn't know it at the time, but I think a lot of the damage that did was a more permanent chemical damage to my intestinal issues and stuff, which persisted. But then that was the first time I was ever aware of what I was eating, not in a negative way, just aware, because I felt full and bloated and things like that.

00:03:38

And then transitioned to secondary school. And I was undiagnosed autistic and ADHD at the time. No diagnosis. No one knew. No one had ever guessed, because I was very good at masking. So I was always seen as the confident one, the centre of attention, all that sort of thing, the one who'd be absolutely fine. And I think it just hit me.

And within a week, I'd just become completely overwhelmed. And that's how it all started. One meal that I refused to eat triggered the domino effect, if you like, and that's how it all started, just from one bit of overwhelm due to undiagnosed neurodivergence. And add in the bowel issues, that added to the overwhelm and things like that as well.

One thing I'd like to add to what you said at the start about men suffering with eating disorders, just while I remember, because my ADHD means I forget stuff otherwise, I personally have... A lot of the data that's coming out actually shows that the number of 1.25 million is actually more like potentially one in seven adults has an eating disorder now, and potentially 50% of children who leave school have what's classed as eating problems, which is a precursor to eating disorders. It's scary, scary numbers.

PS

Staggering.

CB

Yes. That does not surprise me, because unfortunately, eating disorders is something that seems to have a stigma attached to it, and therefore, people are not perhaps actually getting... Talking about it out in the open and seeking support of what they need. So those numbers, as you said, Paul, are staggering, but it actually doesn't surprise me. Particularly with all of the pressure that people are under from media and work pressures and this, that and the other, it isn't surprising. So that started for you at school, aged 11 to 12.

00:05:35

AF

Yes, so quite... I say early. It's not really early. A lot of people start earlier or later, whatever it is. There's no age of onset. There's a lot of... Again, that's a misunderstanding about typical age of onset. You're just as likely to develop an eating disorder when you're an adult as you are when you're an adolescent. So there's no... The statistics don't back up the stereotype on that one either.

CB Yes. And on the Beat UK website, which is what I've been looking at, there are eight types of eating disorders. So I'm just going to list them out. Anorexia nervosa, the acronym AFRID, A F R I D, binge eating disorder, bulimia nervosa, orthorexia, another acronym OSFED, O S F E D, another acronym PICA, P I C A, rumination disorder. So that is quite a lot there. May I ask what type of eating disorder you had?

AF

They've never actually managed to narrow it down. And that's another issue with eating disorders, is if you don't fit a certain exact box, they just put you in the OSFED category, which is other non-specified feeding and eating disorder, which can include a lot of different things, like diabulimia and all that things. But I think mine's... They initially said it was anorexia, because it was due to restriction and things like that. But it's more complex than that, because my personal opinion is that it's more my neurodivergence than the actual eating disorder.

00:07:09

So it's a cross between the anorexia, ARFID and what's classed as atypical anorexia, which is basically anorexia, but you're not underweight, which is again a ridiculous diagnosis but one that's often given. So even, like I said, I don't fit a specific type of eating disorder, if you like, but it's definitely there, and it's been there for a long time and continues to be there at the same time. So yes, quite complex.

CB

Yes. And for people who don't know, are you able to just expand a bit on what anorexia nervosa, that ARFID that you mentioned [overtalking]?

AF

Yes, sure. So in terms of all the eating disorders, I can go through them if you want. So anorexia tends to be restriction of eating, tends to be people who are occupied with wanting to be thinner, lose weight, etc. and tends to be people who are lower in weight, but not always. People who are overweight, are classed as overweight or obese, can also have anorexia. So that's another myth that people don't quite understand.

ARFID is avoidant restrictive food intake disorder, which tends to be... It's very heavily linked to people who are autistic. So people may only be able to eat certain types of food, certain textures of food, certain flavours of food, foods that are cooked in certain ways. So I'll give you an example.

So you get a punnet of blueberries. Every single blueberry will taste slightly different and have a slightly different texture. You get a pack of mini-cheddars, they're all exactly the same. Which one do you think an autistic person who has got issues with food is going to like more or going to trust more?

00:08:46

CB

The crackers.

AF

Exactly that. And that can cause malnutrition. It can cause a lot of different issues with that side of things. And again, that can affect people of all different body sizes as well. And I think that's the main thing for me, is people of all different body sizes can have all different eating disorders.

So you look at binge eating disorder. People can be underweight and have binge eating disorder, because they may purge at the same time. So there's so many different types, but again, I'll stress that less than... I think the latest study they did was in 2019 with the NHS. And only 7% of people with eating disorders were underweight.

CB

That's also really interesting, isn't it?

PS

Yes.

CB

So it is a mental health disorder?

AF

Again, this is contested. And I know I'm not being very exact with what I'm saying here, but we still don't know much about eating disorders. So the contention is there is definitely a mental health element to it. That's undeniable. But there's also growing evidence of biological, genetic influences within eating disorders as well.

00:09:53

So people are genetically predisposed to eating disorders. For example, if you put someone on a restrictive diet, so your weight loss plans or something like that, 25% of those will develop an eating disorder. That's statistics. But we don't know what 25%. 75% will just end up with disordered eating, because it's all disordered eating. All that sort of stuff is disordered eating.

But 25% will end up with an eating disorder. That may be anorexia. It may be bulimia. It may be binge eating disorder. But they will end up with an eating disorder. But we don't know who. So that says that there must be a genetic element and not just an environment element to it at the same time.

CB

Right. And...

AF

So it's very, very complex.

CB

Yes. And there's two things from what you've said. So one, I just wanted to clarify. The term purging, that's when you vomit?

AF

It could be vomiting. It could be using laxatives. People with what's classed as diabulimia, so that's people who have diabetes, can abuse insulin. And other people may use exercise as a form of purging as well. So there's lots of different types of purging.

CB

Thank you for...

00:10:56

PS

It's when you stop eating, isn't it? Is it just simply when you stop? Because I think you can go through phases. I was just reading about how you can... You binge and then you purge.

AF

Yes, so...

PS

And that's symptomatic.

AF

Yes, binge eating disorder tends to be... Not tends to be. It can quite often be binge-restrict cycles. So people restrict. And actually, biologically, if you restrict your intake, your body wants to binge on food, because that's your natural feast-and-famine response.

But that can become an eating disorder due to the mental side of things as well. Some people with binge eating disorder just binge eat constantly because it's like a compulsion to them. So you hear people literally get so hungry, they take three pizzas out the freezer and eat them frozen. It sounds disgusting, but that's the only way they can manage their eating disorder. And how debilitating that must be for them, I can't even imagine.

But yes, so even within eating disorders, there's subtypes as well which can be... Essentially, they affect everyone in different ways, and you can't just... There's no box which will categorise any single person really.

PS

What you're saying, to me, it just highlights, we all eat, don't we? And I think we all have... I think about my family, and we all have ways in which we eat and how we approach it. And that can manifest into something that could be perceived as being a bit of a... You might look at them and go, why are you...?

00:12:24

CB

It's unhealthy.

PS

Yes, it's a bit unhealthy. And I think this is huge. It affects everyone.

AF

Yes.

PS

It's everybody. For everyone.

AF

We live in a society now where disordered eating is normalised. And the difference between disordered eating and an eating disorder is, I think, the mental health side of it and also how it affects your life negatively. But I think that the majority... And this is my personal opinion, but I think it's borne out by just anecdotal evidence. The majority of people have wide classes of disordered eating behaviours in some way, shape or form. And that is mostly due to the way society looks at food, body size, health and all that sort of things.

PS

Do you think it's got worse, Adam? Do you think it's something that, with time, has got...? Is it because we are typically eating more fast food, we're eating in a more unhealthy way collectively in society, or is it something that...? I don't know. I'm interested to hear what you think about that.

AF

I think the modern food environment has a lot to do with it in terms of convenience foods, things like that. But I also think a big issue with it is how people in power have responded and public health bodies have responded to that issue. And they've responded to it in a very binary health messaging in terms of eat less, move more, this is your body size you want to be, this is unhealthy, this is healthy, when actually, it's far more nuanced than that.

00:13:51

They brought in mandatory calorie labelling on foods in 2005 in supermarkets to try and reduce the number of people who were classed as what they class as obese. Guess what happened? The numbers went up. Guess what happens every single time the government brings in what they class as an obesity policy? A, the number of people who are classed as obese goes up. B, the number of people with eating disorders goes up. And C, the number of children with eating disorders goes up. And it's scary.

And what we're now seeing within evidence as well is that biologically, parents who have these disordered eating behaviours and restrict their intake can do permanent metabolic damage to their own bodies, which can actually be passed on to their children as well, which then means their children are more likely to live in larger bodies, be classed as what's overweight, classed as overweight and be put on diets, which then disorders their eating. And it just becomes a perpetual cycle.

PS

Yes, I've seen it. I've seen evidence of that, literally of friends that have impacted their children with how they eat and had to try and steer them. And that in turn has caused a... And actually, what they've done is they've then binged privately and kept food up in their bedrooms or...

00:15:04

AF

Yes.

CB

Talking about this tablet that has helped tackle obesity. And Panorama have got a programme on to say, actually, is this the answer? Is it bringing about more problems? So that would be a very interesting watch, I think.

AF

It's very interesting. And that drug was designed for people with acute complications due to diabetes, who needed a very quick fix to be able to survive. What this drug does is it gives you horrible side effects. Short-term weight loss for sure. As soon as you stop the drug, you gain the weight back on more, because you damage your metabolism, just like any other restrictive diet. So it's more short-term thinking again, and it's going to cause more... In my opinion, it'll cause more damage in the long term.

CB

Yes. And I think, so Paul's question earlier on, do you think it's about junk food, it's not just junk food, is it? It's also this clean eating, and there's the trend for that as well.

AF

Yes. It is so much, and then you add in poverty, and particularly food poverty. And again contrary to popular belief, people with eating disorders are disproportionately in lower-income households. And that again tends to be binge eating disorders, because they only afford what's classed as your fast or your processed foods, which are quite high in energy but quite low in nutrition, which can mean your body then craves more of them, which can make binge eating more likely.

00:16:44

CB

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The other thing that I wanted to ask you, because you'd mentioned about being neurodivergent, ADHD/autistic, and that for you, you feel that that's one of the reasons why you've developed the eating disorder. So now, can you explain that? I think it's because of rituals and having a certain process of doing things. But can you tell me in your words why you think that?

AF

Yes. So it's quite multi-faceted. So the first part is there's definitely a routine element to it. So my autistic side is definitely very routine orientated, same things, same times, all the time, every day, etc. However, the reason my eating disorders have been triggered when they have been is... Now, a lot of people say eating disorders are about control. And for some, they may be. But for me, it's more a safety net.

And I'll explain in terms that my neurodivergent head gets, is that when I'm overwhelmed, when I'm in a state of overwhelm or I can't cope with other things, I go into my own safety net. And my own safety net includes being very, very controlling around food.

00:18:05

I don't know why that happens. But you could say that some autistic people go into certain other ways of coping when they're melting down, addictions, things like that too. And it is, it's a way of... That's your safety net. It's a way of your brain not having to think about things.

You then add in my ADHD at the same time, which is the polar opposite of autism, so my autism wants routine, my ADHD wants compulsivity and spontaneity. So my ADHD happens, it affects me in a couple of ways. Firstly, it affects me because I have an exercise addiction myself. So I compulsively exercise. That is my dopamine-seeking behaviour. That's the way my brain switches off, calms down.

PS

Got one of those.

AF

Yes. And ADHD and addiction are very heavily linked. Mine happens to be exercise.

CB

Yes, I've heard that.

AF

The other way my ADHD affects me is when you try and give me any typical treatments for eating disorders, even autistic people with eating disorders. My ADHD can very well focus on it for a little bit, and then it immediately wants change, and I can't stick to it. So it becomes very difficult to stick to anything that you've started at the same time.

CB

Yes. You are having a constant mental battle with yourself, aren't you?

00:19:22

PS

Yes.

AF

Yes.

CB

So how did it affect you, mentally and physically?

AF

So mentally, when it started, mentally, I was obviously overwhelmed. So I became very reclusive. I didn't want to go to school, bearing in mind that only two or three months before, I was literally the centre of friendship groups, everything, getting top marks in all my exams, all that sort of thing. And I went from that to literally not wanting to go to school, hanging onto the doorstep, trying not to go.

Obviously, I was undiagnosed at the time, so my parents didn't know what to do. The school didn't know what to do, because no one diagnosed me. So for them, it was just behaviour issues. Not for my parents, but for the school especially. I got through that. But it's almost like there's just this constant and this complex trauma that goes on when you're masking for your whole life. And complex post-traumatic stress disorder is a big thing that's more recognised now.

And I think that's the biggest effect it's had on me mentally, that complex stress and trauma that builds up over time and means that my resilience gets less and less every time. So my resilience to change, my resilience to things that are different, my resilience to trying different things becomes less and less, and I get overwhelmed more and more easily, which means I go more and more into my comfort zone.

00:20:44

PS

Adam, can I ask, what made it trigger? Because you were quite young, and I'm just...

AF

Yes.

PS

Interested to know, what got it to a point where literally you suddenly got to a point, clearly, where something is...? Did it switch, or did it just suddenly phase in? How did it...?

AF

Switch. Literally. So I was fine, fine, fine. Obviously, my bowels were an issue, and that started. I moved to the secondary school. I felt fine in myself, but... And then all of a sudden, one day, I just said, I'm not having that meal, and that was it. And I don't know where it came from.

PS

And did you then feel mentally like something had changed?

AF

Yes.

PS

Yes.

AF

It was like a switch which changed everything. And then every single time since that I've had what's classed as relapse, it's been that. So the next time I had a major, major relapse was... Or, yes, which then meant I ended up in hospital, and I've never fully recovered from that, it's why I've got a lot of physical issues now, is I was playing semi-pro football.

00:21:43

So I got myself back to a physical condition I was playing semi-pro football. My bowel issues were still massively issues, but I was managing them as best I could. But then I broke my foot. And I broke my foot, so A, I couldn't exercise. And B, one day, I was on crutches, going into town to have lunch with my friends. My friends walked off. I couldn't eat and be on crutches at the same time, so my food went in the bin. And that triggered it.

CB

Oh, that's...

AF

That one thing triggered it.

CB

Yes.

AF

It's not... And it's amazing how those one little things just go, that's the trigger, that's the trigger.

PS

I literally... And this is just talking totally from personal experiences. I've had moments in my life where it literally has felt like a switch, where some... I can remember being in my kitchen and getting a phone call about something and it being... And I felt like something just switched in me. And then it took me months, years to get back to where I was before that.

AF

100%, yes. Yes, 100%. And people say, oh, was it because of your body, because you were watching the weight? No, it was nothing to do with that. I don't know. I still can't tell you to this day why it happened.

00:22:54

PS

No, but...

AF

I just know it happened.

PS

Yes. That's really interesting.

CB

And then again, obviously then you weren't able to play your sport, so that would've had a compounding thing on...

PS

Yes.

CB

Being able to do...

AF

Yes, I never got back to where I could after that, because I just never recovered properly, so.

CB

So physically then. Let's talk about the physical impacts that [overtalking].

AF

Yes. So the first physical thing was, and again, this was unknown for a lot of years, as soon as my eating disorder started, when I was 11-12, I lost my hormones. My hormones went. And bearing in mind I was 11-12 and I'd just started my adolescence, and I then had no hormones for almost four years completely. I didn't grow. I didn't develop. I actually looked... You look at pictures of me when I'm 11 and when I'm 15, I look younger when I'm 15, because I had no hormones.

CB

My goodness.

00:23:47

AF

But no one knew, because no one ever tested, because they... When you go through eating disorders questionnaires, they always ask if you've got... If you menstruate, have you lost your periods.

CB

Okay, yes.

AF

But they never ask, have you...? They never ask about male hormones.

CB

Yes, that's so interesting.

PS That is true.

AF

It was never asked. So it was never even got. So they went. I didn't develop, and I didn't grow. They then came back for a bit and then went again when I relapsed. And then it took me to go to the GP and say, I don't think I've got any hormones here, for them to diagnose it.

CB

Oh, wow.

AF

Yes. So the effects of that are I basically permanently now have, in terms of developmental terms, a 14/15-year-old's body. And that will never change. That's the best I've got. My body does produce just about enough hormones again now, somehow. I don't know how, but it does. Human bodies are amazing things.

But I'm left with that permanent damage. Now, that obviously gives me more likelihood of osteoporosis in later life. It's definitely linked to the musculoskeletal issues I've got now, because my tendons and my things like that have never fully developed, nor have my muscles. So it's quite difficult. So that's one side of things.

00:25:07

The second side of the physical effects for me, which are probably the most profound if you look at me as a person, is the digestive issues. Now, the digestive issues preceded the eating disorder. So they weren't caused by the eating disorder solely. But they made it a lot worse, obviously. When you restrict your intake, when you're malnourished, your digestive system slows down and doesn't work properly.

Now, I went through a period of a number of years where they were trying to find out what was up with my digestive system, never looking in the right place, to the extent where... And timeline wise, it's quite hard to say exactly, but my bowel, my large bowel prolapsed.

Now, it started as an internal prolapse, which meant it was just difficult for me to do anything. I was in a lot of pain constantly. And I think that started when I was about 15 or 16. And then that became an external prolapse, and the clue's in the name, when I was about 17-18. That remained like that for another two years before it was diagnosed. And again, I diagnosed myself by sticking a camera there and taking a picture...

CB

Yes.

AF And going to the GP and going, that's what's up. It's not [overtalking].

00:26:16

CB

What, they hadn't even looked?

AF

So they'd done a lot... I had a lot of tests done. I had a lot of tests. I had scopes done. I had everything. But they never actually looked at how my bowel was functioning when it was trying to get stuff through it. They were only doing scopes. They were doing biopsies. They were doing tests on my small bowel, when my large bowel was the problem. And then it prolapsed, and they just thought it was piles, or haemorrhoids, which of course it wasn't. It was actually my bowel coming out. So that then prolapsed. So I had...

CB

It sounds so painful.

AF

It was...

PS

Yes, absolutely.

AF

Horrible pain.

PS

And at that age as well, Adam...

AF

Yes, so...

PS

Shouldn't be happening to you at that age. At any age. But at that age, you're young.

00:26:53

AF

Yes. And even when I was playing football, there was a couple of days in school where I would literally go to school and almost pass out with the pain.

CB

Oh.

AF

Have to go home, sleep and then come back in again. Still 100% attendance.
Stupid.

CB Oh my gosh, Adam.

AF

Yes, I know. And again, that's societal pressure on disabled people or... Because I didn't know I was disabled, because I just thought, oh, I've just got bowel issues, right?

CB

Yes.

PS

Oh, [overtalking]. Did you have family? What about your family and your loved ones around you or...?

AF

They...

PS

Could you confide in people?

AF

My parents are the absolute best. They took me around the country, trying to get help constantly. They were the ones... I counted it, and the amount of times they phoned hospitals is in the hundreds. Okay? So they did everything they could and tried everything they could. My brother struggled a lot and has a lot of trauma from what I've been through. I've got a twin. He's a twin brother. We're non-identical twins.

00:27:50

PS

This is the other thing. It's how you impact your loved ones. Because you've got people around you, your parents. If my son was going through anything like you were, I'd be really concerned about it and worried.

AF

Yes, they've seen me literally waste away multiple times. They've seen me very, very low. They've seen me have... Well, the first surgery for my prolapse failed, because I... And then my second one didn't fail, but by that time, the lower part of my digestive system was ulcerating so bad that it wasn't working, which is why I've now got a colostomy bag. So that's three surgeries. After my colostomy bag, I got a major infection, which was another surgery. And I've got to have another one later this year.

And as a parent, I can't imagine how difficult that must be, to see your son go through that, especially when, like you said, they're so young. And they're the ones who kept me going for years and years when I couldn't work and have kept me going while I've been working. And they're the only reason I'm still able to work, to be honest. Because I've never had any professional support means either, so...

PS

[Overtalking].

CB

So no professional support?

AF

None. They've ever accepted me, because I don't fit the right funding brackets or the right brackets for them. Even when I was hospitalised, I didn't fit the right brackets.

00:29:05

CB

So this is a major issue here, isn't it? As you said, not getting support at school because you hadn't been diagnosed as disabled, so trying to fit into this world that the rule-makers decide that we all have to fit into. And then to actually get the professional expertise that you need, you were having to almost beg and say, I am disabled, I am... My body is literally going through...

AF

Yes, I'm struggling here. It's not just in my head.

PS

Yes.

CB

Exactly. And being denied that. I can't believe it. It's shocking. It really is.

AF

Not just being denied, being told it is in your head.

CB

Exactly.

AF

That's one of the discharge summaries I had from one of the leading gastroenterologists in the UK, said it's all psychosomatic, which means it's your brain.

PS

Yes, go home, and just get on with it.

AF

Yes. Spend less time on the toilet was his recommendation.

CB

Honestly?

00:29:57

AF

Yes. And my bowel was already prolapsed by then, so yes.

CB

So you struggled on, still at school, when you were 15, between the ages of 15 and 17, with this.

AF

18.

CB

18.

AF

Yes, through my A-levels as well. I actually had to have an operation three days before one exam.

CB

My goodness.

PS

Adam, you've been through it.

CB

My goodness. So that was one of my questions, was... So I was going to ask you what prompted you to get support, but it was because you were in so much pain, presumably.

AF

Yes, A, when you can't cope because you literally haven't got any energy anymore, and you're like, I don't even know how I'm going to get home tonight. I thought that when I was at uni, I was that bad. But then, the other times, like when you eat something, and then you end up on the floor for three hours because it's so painful, you know something's not right.

00:30:54

CB

And with the OSFED diagnosis, how old were you when you finally got some recognition and diagnosis of the eating disorder?

AF

So, when my parents first took me to the GP when I was 11, the GP said, you've got anorexia. Go home and eat more. So, that was the first time it was mentioned on my medical notes, but then that changed multiple times to atypical anorexia, to, oh, you haven't got an eating disorder, to atypical anorexia again, to OSFED, to you haven't got an eating disorder. Depends who you ask, basically, because they've all got their own opinions on what an eating disorder should look like.

PS

That is terrifying, isn't it, because you're being pulled around and told one thing. You think you have some sort of understanding, and then you're told something completely different by another expert. Yes, you don't know where you are.

AF

Exactly, and the bit that pains me, not for me, but people like my loved ones, really, who see me and see me struggling is that I'm always going to be autistic, I'm always going to have ADHD. That will never change. I was probably always going to have some form of digestive issues, but I would definitely not have the issues I've got now, had the system been set up in a way that it would actually support people from an earlier position and be more aware that eating disorders

are not just what they look like in the stereotype, even within the medical profession.

And that would have avoided a lot of the issues that I've now got, which are permanent. They'll never get better.

00:32:28

CB

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So, why do you think it is a taboo subject? What do you think society can do to help prevent that?

AF

It needs to stop looking at health as a binary thing. So, exercise messaging, new year, new you, exercise more, eat less. Yay, let's all... A, it doesn't work, and, B, it just harms people like me because you're then saying, oh, actually, this new year, I want to exercise less, and people go, what? You want to exercise less? That's not healthy. Yes, it is for me. You say to someone who's got ARFID, who's autistic, oh, well, no, you need to diversify your diet. Don't just eat those crackers.

Actually, they stop eating those crackers, then they don't eat anything, and they've got no nutrition at all, so they end up dying of malnutrition because they've got no nutrition. You blame the parents because all they can eat is burger and chips, but actually that's the only thing that's keeping them going, so that's the healthiest thing for them. And it's this way we look at health and say, well, that's healthy, that's not.

And actually, what health is, is individual for each person. What works for me won't work for you, won't work for anyone else. And that's one way we can help it out. The second way is, we talk about awareness, but 95% of the awareness is looking at 5% of the eating disorders, in terms of anorexia and generally young girls and young women with anorexia. And that tends to be the only thing the media looks at.

00:33:57

I've only ever once seen one article about binge eating disorder, and the comments on that were so disgusting, I never want to see another article. Unfortunately, the only way it's going to change is public health messaging, A, and, B, people being brave enough to put their head above the parapet and put up with some horrifically abusive comments, to say this is me, and this is what I struggle with, and there's more like me too.

CB

Yes, well, anybody listening to this podcast, could you please share it within your friendship group, your work environment, just your networks. Just share it because it's only by bringing this topic out into the open and encouraging this conversation...

AF

if you work with 100 people, 16 people will have an eating disorder. You are not alone. It's not rare, okay. You may not know who it is. They may not know they've got an eating disorder, but they have one. So, it is not rare, it is not uncommon, and there are so many people out there who have it. And actually, the only way we are going to see change in healthcare, in public health messaging, in societal awareness, is by more people talking about it to each other and actively fighting against this.

Either have you got anorexia? Oh, well I wish I had that. I wish I had your self-control. If you've got a binge eating disorder, oh, you're disgusting. That's horrible. No. They're people who are unwell and need support.

00:35:30

PS

Adam, do you think that society still has this perception about what a healthy person looks like and how they need to be slim and beautiful, and what pressures that heaps on everybody, how to look? And if you don't fit into that, still today, people struggle with that, and that then, in turn, can trip and manifest some of these symptoms in various ways?

AF

100%, yes. It is so, so true that society sees health as your average person. If you look on your standard deviation chart, you see an average person. That's what society sees as healthy. Anything under that, no, you're too thin, you need to eat a burger. That's what they say. Anything over that, oh, you're disgusting. You need to diet and lose weight. And that's where the problem comes in, and it starts from an early age because they start weighing kids in school now as well and telling the parents that, oh, they're looking overweight when, no, they're just a healthy kid who's growing in a different way.

Some kids grow up, some kids grow out and then up. It's completely normal. Just let them do it. And by not letting kids do it, we're then putting it onto adults, and by school saying that to... It's just so disordered, and it's so horrible. And health is not a body size. Every single person will have their natural, healthiest body. So, if you ate without restriction, I don't mean anything and everything in sight... Without restriction means trying to honour what your body needs.

Not everyone can do that due to disabilities, so I can't do that, personally, but anyone who hasn't got certain disabilities can do that.

00:37:15

They can honour what their body needs. If you exercise because you actually enjoy it and because it's movement for enjoyment, movement because you love it, for socialising, things like that, not just to burn calories or to lose weight, if people did that, everyone would sit within a spectrum of weight. Some people would be larger, some people would be smaller, some people would be in the middle, but they'd all be healthy because they would all be honouring their body.

And health is not just about physical. It's about mental, financial, emotional, social health as well. And too often, we forget about that and just think, oh, physical health's the only thing that matters, and I think that's the crux of the problem, is we look at health in such a binary way when it's really not.

CB

Yes, focusing way too much on the physical health, which is, in turn, damaging the mental health. So, you've got a multitude of non-physical disabilities. What has been the driving force behind your commitment to sharing your lived experience with others?

AF

I don't want people to go through what I've been through and my family have been through. It's not a selfish thing really. It's more seeing that the 12-year-old boy that I was, I don't want him to ever go through that again. I don't want my brother to have gone through that. I don't want my parents to have gone through that. The fact I know they still are, it kills me because they still are, but...

CB

I was going to say, how do you cope with that? That must be...

00:38:38

AF

It's hard because you want to see change, but you also see the people at the top constantly punching down. And that's not just on mental health services. It's on disabled people in general, the way that disabled people are continuously demonised in the media. So, I've always been very good, academically, in school and stuff, but I've always had a rebellious side, and if someone tells me not to do something, I'll do it.

If someone says, if someone tries to knock you down, you fight back, and that's who I am, and that's who my mum is, and that's how we are as people. I think that's what keeps me going, is the fact that if someone doesn't do it, nothing will happen, and the more people who do it, the more people who will jump on with you. I think that's the way I look at it.

CB

And you work at EFKB. What do you do for them?

AF

So, I work as a traffic planner, so a lot of it is desk-based stuff, but, yes, traffic planner. So, spreadsheets, data, all that fun stuff that lots of people, I'm sure, absolutely love. But, no, I quite like it. I've been at EFKB for six years now, so it was the first full-time job I ever had.

CB

Well, through your co-chairing of the Ability Network, EFKB have become Hidden Disability Sunflower members, so what benefit do you think that brings to your colleagues, the employees?

AF

Visibility. I think visibility is a huge thing. We, me and Victoria, who's the other co-chair of the network, and Gemma, who's a third co-chair, we're very strong advocates of do first, and ask later.

00:40:28

So, we will make ourselves visible, we'll make ourselves known. We'll make things known. We'll put sunflowers all around the office. We'll put, Not all disabilities are visible on the accessible toilet doors, things like that, just to make people aware that, don't judge people by the stereotypes. You can't just know, by looking at someone, if they're disabled or not. And so, for us, it's all about visibility and making people feel safer to be visible as well.

A lot of what you class as invisible disabilities or hidden disabilities are only hidden or invisible because people choose not to look or choose not to ask, or people who are disabled themselves, don't feel safe to talk about it.

CB

In my old company where I used to work, one of my colleagues there, young, younger than me, which is not difficult, but anyway, she's very young, gorgeous girl, inside and out, she often would work from home. And this was before our company really had a working from home policy, if you like. It was, basically, if you had a good relationship with your manager, then you might be able to work from home, kind of thing.

And I can remember people being like, oh, she's favoured. That's why she's being allowed to work from home, because from the outside, she didn't look like she had any health conditions, but she really did.

00:42:04

And being able to work from home one day or two days a week really enabled her to actually be the best employee that she could be because it took out the additional travelling and the fatigue of commuting in and out of Central London, or commuting wherever you live. It doesn't matter where you live. So, you're working from home more now, or less?

AF

Yes, so I work from home roughly three weeks out of every four, basically. I spend one week down in Milton Keynes, which involves travelling and issues. But, for example, when I'm in the office, I can't eat solid foods because of my bowel issues because it just, solid food causes pain. When I'm at home, I can manage it because I can do what I need to do, I can get my hot water bottle out. I can do everything like that and manage it well enough to be able to work.

If I'm in the office, I couldn't do that. So, I literally just can't eat solid food all day. So, I couldn't do that every day, no way. So, one week out of every four is about the most I can do, adding that [overtalking].

PS

Does that suit you, Adam? Is that something that you've sat down with your employer and said, let's work this out and...?

AF

Yes, so me and manager have discussed about it. Now, I say that, one week in every four. If it gets to that one week in every four and I'm not well enough to travel, I just don't travel. We've got that agreement. If I'm not well enough to drive for four hours, I don't drive, so I don't go, and that's just accepted. Especially in the construction industry, I know it's getting better, but that's still quite...

00:43:38

I'm very lucky to have a manager who is so supportive in that way and just says, I'll be guided by you and trust you to get the work done. When I'm at home, some days, if I'm having a bad day, if I have a blockage in my bowel, then I might not be able to start work a bit later. I might have to shoot off halfway through a meeting to, I don't know what.

So, there's so many nuances to it, but I think the best thing I can say about reasonable adjustments is, A, what you were saying, Chantal, is really true. People think, well, if you have it, why can't I have it too, and that's not how reasonable adjustments work, firstly. But, secondly, they're just allowing me to, A, stay in full-time employment, because I wouldn't be able to otherwise, and, B, work the best that I can with the body, with the mind I've got and give me a bit of purpose as well.

And it is just about trusting that I'm not going to ask for something if I don't need it. Disabled people don't take advantage of the system. We don't ask until we're literally at the end of our tether, to be honest with you.

PS

Adam, as you've got older, have you managed to deal with the symptoms in a more controlled way? Is it something you're managing better?

AF

I wish I could say yes, but the problem with my disability is, they're changing all the time. So, my musculoskeletal issues didn't start until about a year and a half ago.

00:45:13

So, a year and a half ago, I was walking, I was running, I was training for a marathon, and now, all of a sudden, I couldn't walk or run. And now, maybe one day a week, I can walk a mile, with stopping in the middle, but the other days, I can barely even walk to the car without pain.

My bowel issues, so a year or two ago, I'd be able to go in the office and have some lunch while I was in the office. I can't do that now because that's got worse. So, the boundaries have changed massively, and my disabilities now take working for, let's say, nine hours including break, and then five around that are me managing my disabilities. So, that's 14/15 of a day, every day, gone. Add in trying to sleep, then you can see why you haven't got much time for anything else.

So, in terms of better, I'd say I'm more pragmatic now about what I'm able to do and setting boundaries and not just saying yes to everything. So, I think, in that sense, yes, and I'm a bit more, don't care about what anyone else thinks. If I can't do something, I'll just say no, and everyone else has got to deal with it. And I don't make excuses anymore. I just say it as it is.

PS

Good for you.

AF

So, I think that confidence has definitely come. But in terms of being able to manage, I think just, when you've got so many unknowns, it can be quite difficult to find any sort of stable management, I think, at the same time.

PS

But it's not easier, it's by no means easier?

00:46:45

AF

No, it's not easier, and the symptoms getting worse, as they have, has made things harder. And as I've been through seeing medical professionals and them saying, well, there's nothing we can do, we're just going to send you to pain clinics, that's, sort of, the end of the line. That's like, there's nothing medical science can do to help you here. We're just going to see if we can manage your pain better. Now, that's hard to deal with when you're 27, to say, actually, well, this is never going to get any better within current medical science, which means for the next 20 years.

So, that's difficult to get your head around, and I think, had I not moved back home to be closer to family, I would have struggled a lot more because I wouldn't have had them to support me at the same time. So, I think that's definitely been a real positive in my life, is making the decision to move back closer to family because they can help me so much more.

And like I say, because my tolerance for overwhelm is getting less and less as the symptoms get worse, the fact that, like this morning, I had to make a phone call to the hospital, my dad came round to be there when I was making the call, just so he was with me. That couldn't have happened if I were living away. So, it's things like that. I've built the support network around me and opened up to them more about how they can help me out, and I think that has definitely made things more manageable.

00:48:07

CB

Good, and I see you've got a Sunflower teddy bear behind you.

PS

I saw that.

AF

Yes, that's my pride of place so everyone... I've made sure it's visible as well, so when I'm in meetings, people can see it.

CB

Brilliant. And so, what advice do you have for someone concerned about a family member or friend, who thinks that they may have an eating disorder?

AF

Firstly, I'm going to... Don't try to fix them because, A, you won't, and, B, they just need your love and compassion. And there's a lot of resources online. So, Beat have some really good resources about how you can help friends and family members. If you are a parent or a guardian of someone who's got an eating disorder, there's a charity called F.E.A.S.T. who are amazing as well. They have support networks for parents and guardians of people with eating disorders.

There's also a charity called First Steps ED, which is based in Lincolnshire, but they give support networks. They can do online counselling, things like that too. So, there's some support networks out there. Secondly, I'd say that all they need is for you to, A... They will open up when they're ready, so it's not like... Obviously, there's criteria, so if they become severely unwell, then you can take things out of their hands, but in general, work with them, not against them.

They are unwell. They're struggling themselves. They are not doing it deliberately.

00:49:37

They're not doing it out of spite, and there will be a lot of arguments. There will be a lot of hard times. God knows, we've been through it as a family, but the best thing my family ever did was, they were just there constantly. They never left, and they tried to work things through with me, so they never tried to give me the answers. They tried to help me make the answers.

I would say, obviously, seek professional support. I'm never going to deny that, but I'm also going to caveat that with, don't be surprised if that doesn't get you to where you think it's going to get you. And I hate to say that, and I really don't want to say it, but I will also say that there are people who do get support and do get really good support. So, always try it, but don't expect that to be the cure, because, often, it won't.

CB

You've got to put the work in as well. So, we'll put links to the two places that you have said, F.E.A.S.T. and...?

AF

F.E.A.S.T. and First Steps as well.

CB

And First Steps. We'll put those in the show notes for people. We always ask any listener who's concerned about any of the content that we discuss, to go to their healthcare practitioner. But, yes, what I'm getting from here is, you've got to do the work yourself, as well as...

AF

You've got to do the work, and you've got to keep hope that... Like I said, I've still got an eating disorder. I've still got an exercise addiction, and I've got permanent damage, but I have my own house. I've got a job. I've got an amazing family.

00:51:09

I've built this life that, yes, it's difficult, and it's very difficult, but it's doable. And with the right support and with the right love and compassion and care around you, that is possible. No matter where you get to on what's classes as recovery, you'll be able to find your life and what matters to you.

CB

That's brilliant, Adam, and thank you so much for giving your time to share about your very personal experience. And as you've said, it's something that you're continuing to work on. It's not just, oh, it's done, I'm great, and everything's wonderful now. And it attests to the resilience, but also to your wonderful family, who have clearly been there for you every step of the way and continue to do so. So, thanks to you, and thanks to your family.

PS

Yes, you're fortunate, Adam. And thanks. I've really enjoyed having a chat with you today, and it's lovely to meet you and just appreciate the fact that you've been so open with us and shared your experiences and points of view. And they're really valid, and I think they're going to help inform others about your conditions. And just wish you all the best, the very best.

AF

Oh, thanks so much, Paul. Thank you.

CB

If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner. If you enjoyed this podcast, please share it. Leave a rating and review to help raise awareness of non-visible disabilities and the Hidden Disabilities Sunflower. You can also follow and subscribe to The Sunflower Conversations podcast.

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