

Eating Disorders with Zoe Summers

Speaker Key:

NA Narrator

CB Chantal Boyle

ZS Zoe Summers

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

CB

Before we start the interview, I just wanted to issue a content warning. Today's topic is eating disorders, and throughout the podcast, our guest 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 my guest today is Zoe Summers. Zoe is going to talk to us about eating disorders. It remains a taboo subject which can be lethal. Through Zoe's lived experience, she has become an ambassador for the eating disorder charity, Beat UK. Hi, Zoe, thanks for joining us on The Sunflower Conversations podcast today. How are you doing?

ZS

Hi, thanks for having me. Really glad to be here. Thanks for having me and, yes, really well, thank you.

CB

Well, this is a really nice opportunity for us to catch up. We used to work together in a previous company and I guess at the time, well, I know for a fact at the time, I didn't know that you had an eating disorder and I saw one of your posts that you made in your role as ambassador for Beat UK and I just thought, well, first of all, gosh, this is something I did not know about you.

00:01:46

Second of all, what a fantastic thing to be an ambassador for, to support other people through this. So, I guess when we think about I didn't know it, well, why wouldn't I know

it. It's a taboo subject and hopefully we can help bring it out of the shade and into the light with our conversation today. So, thanks, again, for giving us your time.

ZS

Of course. Yes, I love talking about it now. I've gone from not telling anybody and being completely shrouded by shame and secrecy to wanting to talk about it as much as possible. So, yes, really happy to be here and discuss it with you.

CB

Thank you. So, Beat UK estimate that 1.25 million people have an eating disorder in the UK and I take it that many people don't get diagnosis, so the number of that could be considerably higher.

ZS

Yes, I think that's very likely to be true, and I think also, even if somebody isn't suffering with a fully-formed eating disorder, there are certainly, I think it's very fair to say, people who might be struggling with their relationship with food and they might be in a situation where, if they had certain circumstances and conditions, they might develop an eating disorder.

00:03:11

So, yes, there are certainly people out there who might have issues with disordered eating but not necessarily a fully-formed eating disorder as well.

CB

That's great. Can you actually then just give us an overview description of what an eating disorder is and whether or not it's termed as a mental health disorder?

ZS

Yes, of course. I should say first off that I'm not an expert. I'm obviously a lived experience volunteer but I've been doing this for quite a while now and I talk and see a lot of people who are struggling with eating disorders on a really regular basis and I attend a lot of events and I think it's really important to be aware that eating disorders are a really complex mental illness.

I think the way that the media portrays them can be really stereotypical and, as you say, they're quite a taboo subject. I think that the broader conversation about mental health is definitely improving and people are opening up a bit more and there's a more accessible discussion about mental health but I think we're a little bit behind with eating disorders and I'm really hoping that that trajectory changes and that people talk about them more openly.

But, yes, according to the Beat website, they are absolutely defined as a complex mental illness and they are usually defined by having a distressing or difficult

relationship with food that will be deemed as unhealthy for your mental and physical health.

00:04:33

CB

Thank you. I've had a look at the website as well and I've discovered that there are eight different types of eating disorders but I guess there may even be layers behind those. The ones that are on the website are anorexia nervosa. Is it Arfid, is that how you say it? A-R-F-I-D.

ZS

I always say Arfid but I don't know. I think people pronounce it differently.

CB

There's binge eating disorder, there's bulimia nervosa, there's orthorexia, there's OSFED, PICA... I can't say it. Can you say it for me?

ZS

Is it rumination disorder?

CB

Yes, rumination disorder. Some of these I hadn't heard of before. I've heard of anorexia nervosa, I've heard of bulimia and binge eating disorder and the others I hadn't heard of. You're not an expert, as you've said, but I wondered if you were able to perhaps talk me through some of them, the difference between anorexia and bulimia?

ZS

Yes, of course. Most people have heard about anorexia and bulimia. Anorexia tends to be... It presents as being really, really restrictive, having really, really restrictive diets and restrictions on a daily basis, which can often go to quite an extreme place.

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Anorexia typically tends to be people with a very low BMI but it's not necessarily always the case. I think it's really important to acknowledge that people with larger bodies can also suffer with anorexia, and that's definitely something that you don't see as often in terms of how anorexia is described and presented by the media. So, that's very much about a really, really severe level of restriction and control with food.

And then bulimia is much more about purging, and I won't go into too much detail but I imagine most people have a sense of what bulimia is. It tends to be much more about trying to compensate for whatever food choices that person has made by over-exercising or purging in other ways.

CB

In our pre-chat, you mentioned about PICA. What's PICA?

ZS

PICA, that's one of the ones that I think hardly anyone has heard of. And I don't know a huge amount about PICA but I've learnt a bit about it more recently, and it seems to be more common among children who might have other illnesses, and it's essentially a disorder where the person consumes substances that aren't food, that don't have nutritional value.

CB

So, that can be also linked with when women are pregnant, can't it? I know somebody who was eating soap and she just couldn't stop. I met her. She had a bar of soap and she used to just scrape it up with her nail and just have it throughout the day. And it wasn't something that she would do outside of her pregnancy but when she was pregnant, the craving for it was quite intense.

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I'm not saying that she had an eating disorder because that was linked to something that was happening with her hormones whilst she was pregnant, but that's the kind of thing that you mean.

ZS

Yes. I don't have lived experience of PICA but that's certainly what I've read about it, and it does seem to be a lot more common among children. Obviously not really young children because we all know that a two-year old is very likely to put something in their mouth that isn't food and that's completely normal. But it's much more about how that might potentially continue into being five-, six-, seven-year olds. Yes, that's just one of many eating disorders that people haven't really heard of and don't really talk about.

CB

Can you tell me a little bit about orthorexia?

ZS

Yes, I'm really, really passionate about this because this is definitely something that I've had lived experience of. So, just to be totally open, my eating disorder started out as binge eating disorder and then it morphed into bulimia nervosa but across the whole process of that happening, I definitely had tendencies that presented as being very orthorexic as well. So, it's a real mix of things.

Orthorexia is essentially an obsession with pure food, pure being in air quotes. There's been a huge movement, which I'm sure everyone has been exposed to one way or

another, around clean eating over the last 20, 25 years or so, particularly the way that clean eating is promoted on social media by influencers.

00:09:26

CB

Can you explain clean eating for people that have no idea what that is?

ZS

Yes, of course. Clean eating is typically a term that's used to describe cutting out any foods that might be processed in any way and there's a lot of fearmongering around it. The idea that you're not eating purely enough, unless you're eating just purely whole foods, foods that are really known for being really nutritionally dense.

It's the idea that you're a failure if you don't eat those pure foods, which actually, in our Western societies, is not the most accessible dieting choice. Arguably, it's not the healthiest choice for a lot of people because food has all sorts of value to us, including nutrition, but it also has emotional value.

Food is part of our culture, it's part of our customs, it's part of how we socialise and connect with other people. So, having a really restrictive diet that focusses purely on clean eating and this really elitist rhetoric around food. I know, obviously, a lot of people who engage in that and think they're doing something really good for themselves and if they're really enjoying it and they've got a great relationship with food and they feel really happy, then crack on, I wouldn't want to judge anyone for their food choices.

But, unfortunately, I do think there's definitely been a correlation between that rise in discourse around pure foods, clean eating, cutting out anything that's been processed, even though largely most foods have been processed in some way, there's definitely a correlation there between reaching where we have a really unhealthy obsession that leads to a lot of anxiety, a lot of other mental and physical symptoms.

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And, actually, people with orthorexia are often known to cut out major food groups that can lead to nutritional deficiencies. So, yes, it's quite problematic and it's very difficult, I think, to treat because a lot of orthorexic behaviours are very similar to behaviours that might be deemed as health-promoting behaviours and I think that's what makes it quite difficult to diagnose and to treat. But there's a lot more conversations around that happening at the moment and it's definitely being talked about a bit more.

CB

Yes, because I would imagine if you started down that route with the clean eating, you're doing it because you think I want to have a lifestyle change, I want to just put nothing but goodness into me. So, for that to then develop into something that actually could be very damaging to you is something that would be unexpected.

ZS

I think a lot of people have the absolute best of intentions and they're just trying to do the absolute best thing for their body and to feel good and to get that healthy glow that people talk about. But I think it's really important, when people are considering making those changes, to just think a bit more exploratively about their relationship with food. What is it that they need from food? What is it that is important that they get from food?

00:12:29

Because I think, arguably, for the vast majority of us it's not just nutrition. Because if it was, I would just eat broccoli and chicken and vegetables every day. But I absolutely do not because my relationship with food is more complex than that and there are other things that I need from food. I think that's a conversation people don't tend to have.

CB

For example, I'm thinking biscuits. I used to have... Well, I still do have one and there aren't any at the moment because I'm waiting for payday but there's usually biscuits in the cupboard and what I found I was doing is that I was going to the cupboard whilst I was doing something and I'd break a biscuit in half and then eat it as I was going around doing something, so I'm not really eating it.

And then later on I'd maybe go and get the other half. I recognised that I was doing this and then I was like if you're going to eat it, actually sit down with a cup of tea and taste it and enjoy it. This is a stupid way because you're going to eat it anyway but you're denying yourself to be in it.

ZS

That's really interesting, yes.

CB

So, it was the relationship of like I want to eat the biscuit, it tastes really nice but I'm telling myself I shouldn't really eat it, so if I do it like this it's not really happening.

ZS

Yes, I think that's quite common. And it's understandable because so many foods are really demonised and there's a lot of really common discourse around food guilt and having to burn off what you eat and all that kind of stuff. Again, I know a lot of it comes from a really well-intentioned place and it's absolutely fine to be health conscious.

00:14:12

But when your mental health is starting to be affected by your relationship with food because you're placing these food rules on yourself. The dietician that I worked in recovery called it the food police. The food police are here again today. It can really

backfire and I think for a lot of people it's actually much more healthy to have a balance and to just be kind to yourself.

I'm obviously not a dietician or a nutritionist but having worked with a dietician in recovery, I definitely got the impression that there is room for treats. You're not necessarily going to drop dead tomorrow if you enjoy your biscuit with your cup of tea. It might be that the media or the influencer community make you feel very differently about that.

CB

Yes, absolutely. One of the questions that I had, and it's about the link to mental health, and, as I said, I don't know very much about this, so this is why I'm really happy to talk to you and increase my learning and understanding. With some of the eating disorders, I know one in particular but I can't remember which one it was, is that it's like you've got a little voice talking to you, telling you don't have this and don't do that.

It's like another being with you and that influences and it's very difficult to fight against that voice, to tell you what you should and shouldn't have. Do you know whether this is a common trait for most of the eating disorders?

00:15:48

ZS

Really interesting you ask that, actually, because I was reading another story from a lived experience volunteer. I think it was maybe last week, so very recently. She spoke about how even though a lot of people with lived experience describe that exact experience and describe having this voice in their head that would really delay their recovery, she personally didn't experience that. I don't think it's necessarily linked to a specific ED but I think it's fair to say that among the recovery community, it does seem to be quite common.

From my own personal experience, I definitely think I'd started to develop a sense of identity that was highly linked to my eating disorder. I think identity is often quite a key facet of the development of eating disorders psychologically. Certainly for me it was. It became a really major aspect of my identity and a lot of the work that I did with my therapist and my dietician was really unpicking that and learning to appreciate that people don't love me for the size of my body or the food choices that I make.

And I think because it can become so enmeshed in identity and your sense of self, it's very easy to have these really intrusive thoughts and thoughts that are very much about control and perfectionist thinking and guilt. Guilt and shame are very big ones and very major ones.

Very, very common among the ED recovery community. I think they can feel like a voice, especially with it being so linked to having an inner critic and being very perfectionistic. Obviously that's not for everyone with an eating disorder but I definitely have met many,

many people in the recovery community that have perfectionistic tendencies and then that voice becomes very loud.

00:17:47

CB

Yes, that's very interesting. I was going to ask you, and this is a massive question, do we know why eating disorders develop?

ZS

That's a really... Well, I would love to be able to just reel off studies and statistics. I don't think we really know. I should caveat again that I'm a volunteer but I've read studies, I've listened to lots of interviews, I've read lots of books. I'm actually hoping to retrain to become a psychotherapist to help treat eating disorders because I've become so passionate about it but I'm very much in the early years of my studies.

From everything that I've read and heard, there do seem to be lots of links with... It obviously depends on what eating disorder you have but especially with some of the more common ones, a lot of it is about how we feel. It's not actually about the food, it's about our relationship to ourselves and how we feel and how we deal with our feelings. If you look at something like the pandemic, that was really interesting in terms of how eating disorders manifested in the pandemic.

It was quite interesting to see that... Well, interesting and very saddening to see that they skyrocketed and I think it goes to show that some people who may be on the verge of disordered eating, you might have a troubled relationship with food but don't necessarily have a fully-fledged eating disorder, it might be that if their conditions change and they're more isolated and they've got more time to ruminate on something like their relationship with food, maybe it's something that they can control as well.

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I've definitely met with people who are struggling with eating disorders before who've spoken a lot about not being in control of their lives and that's quite common an aspect of depression as well, is that feeling that you don't have control of your own life. So, that seems to be quite a common thread among, certainly people that I've spoken to who are in recovery.

But, yes, all I can really say is that we seem to know that it's definitely around dealing with feelings. To speak more specifically to binge eating disorder as well, one of the main things that I had to deal with was really challenge my black and white thinking and restriction.

CB

Explain.

ZS

The more that I dieted and restricted, the worse my binge eating became because my body was clearly desperate for some satisfaction, some calories and for all of the other things that food had been providing me up to that point. I really, really genuinely feel that that was one of the main things that fuelled my binge eating, was just restriction and dieting.

So, I think that while that might not be common for everyone with eating disorders, it's definitely fair to say that on the whole eating disorders are about a lot more than the food, particularly with binge eating. If anyone out there is struggling with binge eating, it's definitely important to really sit down and think about how much you're restricting.

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And restrictions don't have to just be, oh, I'm on a calorie-controlled diet or I'm cutting out X, Y and Z. They can be very small things, like very small mental restrictions. So, for me, I had things like, oh, I shouldn't be eating after 6 PM. I'd be desperately eating at ten to six and if I ate after six it would be this big drastic failure. Why? Very, very small things.

I had this thing where I really, really didn't feel like I was ever allowed to eat convenience foods at train stations and things. If I was travelling, I'd always try and take my own food, so I could make sure that I knew what was in it and I knew where it was coming from. Again, that's where it becomes quite a grey area because some people might do that genuinely because they love food prep and they love making themselves a nice salad to eat on the way to work.

But for me that became a huge source of stress and anxiety and I had such a preoccupation with my diet that I wouldn't be thinking about anything else, and if something happened one day and I just needed to eat for a practical reason at a food outlet at Victoria Station, for me that would be the biggest failure of the week. That would very disproportionately become a huge, huge issue for me.

00:22:10

CB

How would you deal with that emotion?

ZS

I didn't really deal with it at all. I would just beat myself up, actually, and just give myself a really hard time. And I would just ruminate on it for days and days and I would think about ways to purge or make up for my failings, which I think is, unfortunately, really common.

I think that inner critic just makes your shame so loud and, unfortunately, I think, especially with things like binge eating and bulimia, there's so much shame and

secrecy associated with those illnesses, that it just really, really prolongs your illness because you don't know you can open and talk to people about it.

That's another reason that I'm so passionate about doing this, because now, having had treatment and come out on the other side, I've got a great relationship with food. Occasionally I have to challenge myself with body image because body image is a difficult long road.

I would say it definitely is a journey and not a destination but overall I'm in a really good place mentally now, and now that I can see what all of these issues were and I've challenged my food police, I've done all this work, the main thing that I want to really hit home with people is that being vulnerable and open is such a fantastic first step towards recovery.

So, if you do have anyone that you can trust, that you feel comfortable opening up to, it's a really, really fantastic way of just getting a little bit of relief. I literally felt my whole body just lighten when I started to tell people that I had a problem. It's obviously very scary but I think it's a really important step into eliminating that shame and the smaller you can make that shame, the more space mentally, the more bandwidth you have to recover.

00:23:58

CB

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I've had past experiences with purging but how I rationalised it was that it wasn't anything to do with any eating disorder, it was just this involuntary thing that would happen and deep down it was all to do with body image and size. You've mentioned a lot about the media throughout our conversation. What, in your opinion, is the problem with the media?

ZS

Gosh, I could talk about that for hours, Chantal. That's such a big question.

CB

A few examples of where you think it's causing damage.

ZS

Yes. There are a lot of issues, I think, with black and white reporting that portrays thinness as the absolute ideal and anything other than thinness as being unhealthy and not worthy in some way. Obviously, we're all grappling with a constant bombardment of content and advertisements that portray a very, very specific and usually very unobtainable beauty deal that I think is only realistically achievable from a very, very,

tiny, tiny proportion of the population. There's also editing and AI which take things to a whole new level of...

00:25:37

CB

Heavy editing.

ZS

Heavy editing, absolutely. One of the things that I did as part of my recovery, which I'd highly recommend everyone to do, if they just need a little bit of a boost and they feel like they're actually following accounts that make them feel rubbish, I started following accounts that worked to expose a lot of that editing and they'll stand in a pose...

They'll say, this is the same body within five minutes of taking two photos. One of them is edited and has certain poses and lighting, one of them is not. And you'll see two what feels like very different bodies. One of them feels a lot more realistic and diverse and the kind of body you might see if you pop out and go for a walk. The other body is the kind of thing that you only see on Instagram.

CB

I noticed that Marks and Spencer's, they would... I don't know if they're still doing it but they were doing advertising by using reels on Instagram and they used women of all different sizes and shapes actually wearing the same outfit. So, it was them going to their wardrobe and shaking out, this very trendy way these reels are done, a jumper and putting on the trousers and you could see that these outfits were being designed for women of all sizes and all shapes and it felt very real.

ZS

Yes, I love that.

CB

Yes, it's a really, really nice engaging way and I don't think anybody would look at them and think that's not been designed for me or I've got to get myself to look in this particular... I've got to increase my height by whatever and so, yes, much more real and achievable without putting pressure on us to look a certain way.

ZS

I think the media, hopefully, is going in that direction a little bit more because I think brands are starting to realise that they don't just have to always focus on being aspirational. They also have to be relatable, they have to give good representation and they have to feel accessible, welcoming, inclusive. These are words that you're seeing pop up all the time.

00:27:49

So, I'm really hopeful that we'll see more of that. Because essentially if the only body that you're portraying represents an incredibly small portion of people, there's nothing inclusive about that.

CB

No.

ZS

So, I think that's really, really important to acknowledge and, yes, certainly having a think about if you are struggling with food or body image in any way, which I know a lot of people are, I think it's really valuable to just have a look at who you follow and just be curious but also a little bit interrogating with how you follow certain accounts on social media. Obviously everyone likes following a celebrity. I'm always going to follow Pedro Pascal until the day I die. There's a lot of celebrities, women who have really unobtainable bodies, who I do follow.

But it's also how they talk about their body. Are they saying if you buy this product you can look like me? Because, obviously, a lot of people are also doing that because there's a lot of money to be made in that field.

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There's also a lot of misinformation and there's some really disturbing content floating around, I think, particularly on TikTok which is very worrying, given the age of the people who are on TikTok, telling people this is the calories you should be consuming.

There's all of these what I eat in a day videos that will start with a body check, somebody in a mirror showing off their very toned slim body and then it'll show you what they eat in a day. They're really popular and it's fine if you are inspired by new food ideas, recipes. I've seen some great what I eat in a day videos and, oh, yes, I'm going to make some of those things. They look delicious. They look like a really nice way of introducing a vegetable into my day that I wouldn't usually eat.

Sometimes they can be genuinely quite inspirational and I don't want to take that away from anybody. But especially is they start with a body check, there's definitely a very clear implication and message there, that if you eat like this, you might look like me, which is just not true.

We all have different biological make-up, we have different genetics, we have different lifestyles, we have all sorts of different health markers that will inform our size and simply changing your diet to eat the way that an influencer does is highly likely to make no change to that and it could potentially damage your relationship with food in other ways.

CB

That's right.

ZS

There's lots of stuff out there that is not helpful.

CB

When did you decide to...? What prompted you, rather, to seek support? When did you come to the realisation that this was a problem for you?

00:30:16

ZS

Much later than I wish I had. Much later. I'd basically had disordered eating issues on and off for my whole life. I'd had real peaks and troughs with it. There were definitely periods in my life where my ED was less impactful and I didn't necessarily feel that I had too much of a problem. And then there'd be other periods where it really kicked off.

I didn't really click that I actually had an eating disorder at those moments but I did eventually end up getting really, really sick and it was when I'd basically decided to make a more intentional effort to change my body and I was doing a lot more exercise and restricting. I remember at the start of the process thinking I'm really mentally self-aware. I'm going to be fine doing this.

I'm going to check in with myself, I'm going to journal, I'm going to make sure that I still eat foods I enjoy. I actually felt like I went into it in a relatively self-aware way because I did recognise that I'd had issues with food in the past. So, I genuinely thought I was going to be fine and, unfortunately, that just wasn't the case at all. Within four or five months I'd become so obsessed and so mentally unwell and in such a bad place, and it got to the point where I just said to myself, I really hate food at the moment.

00:31:37

I really hate my body and I really hate food and I love food. I love cooking, I love baking, so I really knew at that moment that something had gone horribly wrong and that I just wasn't okay. I had to really, really look in the mirror and face up to the fact that my relationship with food was just completely dismantled. My happiness, my confidence, my self-worth was just in completely the wrong place and all the wrong alignments, all the wrong values and I really had to just face up to that.

And especially because I had been journaling, it was quite easy to see the evidence that something wasn't right because I could look at the pages and I remember looking at one page that said something like I think I'm more mentally ill right now than I've ever been in my life. To have that in writing...

CB

Written by you.

ZS

Yes. That's a pretty reliable narrator. I remember that day really vividly and it was obviously really, really upsetting to read but it also felt weirdly freeing because I'd finally reached a point of acceptance and acknowledgement. I think up to then I'd maybe made a few comments to friends that I was having some anxieties around food but I'm so careful to never say I've got an eating disorder because that felt like such a difficult label to swallow.

But seeking help is a really, really important step once you've made that acknowledgement and I think because I knew that there was no going back and I'd written it down, I'm going to seek help, that gave me the kick that I needed to start seeking support.

CB

Good. And then you've had, you mentioned, therapy and a dietician, a combination of the two of them that's helped to get you to where you are with your recovery.

00:33:29

ZS

Yes, absolutely. The therapy side was really important because I've definitely had childhood experience that for me personally, I think, have contributed to me having troubles with food and body image and self-worth as well. So, that was a lot of what I unpicked in therapy which really, really helped and got me to a place of much more acceptance and compassion and kindness which I think we could all do with but I really needed it at that moment for that process to be effective.

And then the dietician side was much more about challenging all of these food rules that I'd created for myself, learning to eat more intuitively was a massive, massive gamechanger for me.

CB

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ZS

And I know intuitive eating... I don't know if you've heard of intuitive eating but there's quite a lot of misinformation about that online as well. There is about everything.

CB

What is it? I'm thinking intuitive eating is eating what you feel like you want when you want it but it can't be as simple as that, is it?

00:34:32

ZS

It's fairly self-explanatory but it was essentially coined by two dieticians, I think both of them are in the US, and they wrote a book which is about really revolutionising your relationship with food, learning to really trust your body, and there are ten principles to it which stem from challenging your food rules to things like moving more intuitively as well. A lot of people who are in eating disorder recovery feel very scared to return to any kind of exercise because they've had such a difficult experience with exercise that's become very unhealthy.

But we all know that movement is good for us and it can be hugely beneficial for our health, mentally and physically, if it's done in a way that makes us feel good and isn't contributing to other problems. So, a lot of it is about reclaiming movement and moving in a way that feels good to you and also about nutrition but it's gentle nutrition. So, how can we introduce nutrition the way that isn't full of restrictions and shame and negativity and having to eat privately or whatever these issues might be.

How can we, in a way that gives us satisfaction, makes us feel satiated, gives us variety, has room for foods we enjoy but still makes us feel good? Because, actually, if you do eat... I think a lot of people genuinely think intuitive eating is just eating pizza every day, all day every day, or just doughnut after doughnut after doughnut, but I think it's fair to say that most people wouldn't feel very good if they did that all the time.

00:36:03

So, that's what's the big misunderstanding is around intuitive eating, I think, especially when you see content about it on TikTok. But it's a really, really nice approach.

Obviously it doesn't necessarily work for everyone but it was a really key aspect in my recovery, personally. So, learning about, yes, just really trusting my body and it really helps you understand your hunger and fullness cues as well.

Because when you've been dieting on and off for years and you've had a really damaged relationship with food, I got to the point where I didn't even really know if I was hungry or full. So, that was a huge gamechanger for me as well and that was the main thing that I worked on with my dietician and just really, really challenging restriction.

CB

Yes. I think having access to a dietician must be a gamechanger.

ZS

Yes.

CB

Who can really explain to you how the body needs nourishment and how you get that nourishment and why it's so important. I think that must be... Do you know whether that is something which is offered as part of an NHS care package?

ZS

It really depends what eating disorder you have. I definitely think binge eating disorder is something that health authorities all over the world are trying to prioritise a bit more and learn more about because it's very under-researched, it's still quite misunderstood.

00:37:27

I think generally eating disorders, they're still under-researched and misunderstood more broadly and there's a lot of focus on weight restoration and getting to the right BMI. Obviously there's also therapeutic approaches. I think usually they might give you access to something like CBT, which can be helpful, but I didn't manage to get... My dietician, honestly, I don't think I would have recovered without her and she specialised in binge eating and repairing your relationship with food.

A lot of other dieticians don't focus on that at all. So, I think it's really important, if you are looking at working with a dietician for something as specific as that, make sure that you find somebody who has that as a specialism, and there are lots of dieticians out there who do work in that field but, unfortunately, I don't think they're necessarily accessible through the NHS and that's not something I experienced.

I think things are changing. I think there's a lot more interest in understanding binge eating and understanding bulimia and hopefully things will continue to improve. But I was really... I should acknowledge my privilege because the only way that I was able to access a therapist and a dietician at that time when I really needed them was privately.

And the other challenge, I think, with healthcare is sometimes there's a consensus that you might not be sick enough, so people end up making themselves more ill so they can get the support they need. And I know that's been widely acknowledged as an issue but it's just so sad. So, widening access to support is so important and that's another reason that I'm so passionate about what Beat are doing because self-help and support groups aren't always enough but they can certainly help to ground and support people who are on waiting lists.

00:39:03

And a lot of the people that we speak to in things like the Beat Support Services, they have chat rooms, for example. A lot of the people that we chat to on there are people who do know they have an issue and they're ready to get the support they need. But they're on a waiting list, so they need community to see them through that wait, because it's a really difficult time.

They also offer a lot of support to carers as well. So, loved ones and carers who might have a child or loved one with an eating disorder, it can be hugely draining and stressful for them. So, that's another thing that Beat are really good at doing, is offering that support to carers and connecting you with local support services, so you can get additional support potentially while you're waiting for care from the NHS.

CB

That's great to know because the impact on the wider family is also significant, isn't it? To watch a loved one having to go through these challenges and pain.

ZS

There are quite a few volunteers as well in the lived experience volunteer community who haven't... Obviously there are people who've had lived experience of experiencing an ED, like I have, but there are also lots of volunteers who've been carers. So, if you're a parent and you're concerned about a child, they can potentially connect you with other carers who've had shared experiences and that can be really valuable as well.

00:40:24

CB

What do you think about the Hidden Disabilities Sunflower and the ways in which it can support people who have got an eating disorder? I'm thinking about in work situations when people roll out the biscuits and the cakes on birthdays, things like that, or when you're out with friends for a meal.

ZS

I think it's a really interesting thing to explore and I'm really pleased that it's being considered to be something that would really help people who might be struggling who don't feel they can really verbalise what they're suffering with because there are a lot of cultural and social enablers and workplace enablers too for eating disorders. People just don't always fully realise the gravity and impact of comments that they make.

I still on a regular basis will have friends that will call me greedy for ordering a side dish in a restaurant or they'll make jokes about me having that third biscuit, or whatever it might be, and actually I can shake those comments off now, even though sometimes I find them a bit annoying, but when I was really sick, they would totally ruin my day. They would make me feel so unworthy and so upset because I had completely aligned my identity and self-worth with my diet choices, essentially.

So, I think a lot of distress can be happening in an office space, in a gym, in a restaurant and it might well be that someone is struggling so much with communicating what they're struggling with and all of the shame and secrecy we talked about. So, I think having something there as a reminder, that there are sensitivities there and that comments on food and body could have a really significant impact on you in those sorts of settings, could be really helpful for people.

00:42:17

So, I think it's really, really good that that's being explored. Because, as we've talked about, you really can't tell if someone has an eating disorder just by looking at them. We can make assumptions but we really have no idea and you can be any size, any age, any cultural background, any ethnicity and could still be struggling.

CB

I think that's great words that you've said there. I think the thing about, oh, that's a big greedy, having that, or, conversely, why aren't you ordering anything.

ZS

Yes, absolutely. Yes, I've definitely spoken to other volunteers who have been in recovery for particularly anorexia who find social eating extremely stressful at times and being challenged about leaving food on their plate or having a small portion or choosing a certain food or declining another type of food.

I genuinely think that things will just be a lot easier if people didn't comment on people's food choices because bodies and brains are very complex, very diverse and we don't know what anyone else is going through, what they may have eaten that day, what their relationship with food is like at that time. People have got very contextual reasons for their food choices, so I think in general it's just a lot easier not to comment. Just focus on your own.

00:43:39

CB

What advice have you got for someone who's concerned about a family member or friend who they think may have an eating disorder?

ZS

I get asked this a lot and I think it's obviously going to be quite individualistic and it's going to be quite dependent on the relationship. I certainly think if it's somebody you're very close to and you've been able to have quite vulnerable conversations with them in the past and you feel like they might open up to you, as I mentioned before, at least personally from my experience, starting to feel more comfortable opening up and being brave enough to speak about my difficulties was a really important first step for me.

So, being able to potentially be that person that someone can open up to, it can be quite difficult. It can feel scary, it can feel draining and in certain circumstances it might not be appropriate. But especially if you've got a really close trusting relationship and you've got a strong bond, making yourself available and genuinely asking somebody if they're okay in a way that is clearly really authentic and well-intentioned and isn't just a, oh, hi, how are you. Because obviously when you say that, everyone's going to say, yes, I'm fine.

CB

It's the standard answer, fine.

ZS

Exactly, yes. People say it on autopilot, don't they?

CB

Yes.

00:44:54

ZS

But I think showing that you genuinely care is really important but I also think it's highly, highly important to avoid commenting on their food choices because I don't really know anyone in the recovery community who's found that helpful. It can make them incredibly anxious and I think especially if you're in a similar situation to me, which is where your food choice is a really integral part of your identity and it's all become very enmeshed, it can really, really bring up the defence mechanisms and I would just immediately have a defence mechanism and a barrier pop up straightaway.

So, I don't think it's very effective. But I think generally as well talking more openly about wanting to explore your relationship with food and improve it is just not a conversation that people really have and there are some great ways of exploring your relationship with food and just wanting to make it more positive and obviously focus on nutrition but focus on it in a way that is gentle, that is realistic, that still enables you to enjoy life.

I think having those sorts of conversations can be quite useful but it's just very important to be gentle in your approach and don't comment on the food and body, don't comment on weight, don't ask somebody how much they weigh and try to signpost to resources. You don't have to take somebody's mental illness and their recovery on your shoulders. No one should have to do that and, obviously, if it's a loved one, it's going to feel really important to you for them to get help. But there's also so much expertise out there.

00:46:30

Even if you are on a waitlist, for example, for care through the NHS and I fully appreciate that a lot of people can't afford private care, then that's where services like Beat become so, so important. So, doing a bit of signposting, if you feel comfortable to do so. If somebody has started to say... They might not say, oh, I fully acknowledge that I have an eating disorder, because that's such a difficult thing to do.

But maybe they'll say something like, oh, I am feeling a bit stressed about food, I'm not feeling very good about my diet, I'm feeling really anxious about my body and I'm struggling with food choices, that kind of thing, maybe if someone says something like that, you can say, oh, well, have you considered talking to anyone at Beat.

They're not just for people who've had a diagnosis of an eating disorder, there's a lot of resources around how to make sure that your relationship with food is healthy and strong and you still enjoy food. So, I think that's quite a nice way of gently introducing and signposting without making somebody feel threatened or bombarded.

CB

Yes. I'm thinking about a personal experience of me being a bit concerned about somebody close to me and what they're doing and trying to approach it without upsetting them.

ZS

Yes, it's really very sensitive.

CB

It's really difficult, isn't it?

ZS

Yes.

00:47:46

CB

Because it is generally something you do in secret and you're not really chatting to other people about it. And so to feel that what you've been doing has been noticed, sometimes a person may feel like they've been caught out.

ZS

Yes, absolutely.

CB That's the difficulty in trying to approach it with somebody who hasn't acknowledged it, isn't talking about it and it's just... But I think, again, here we should refer people to Beat UK website where there's lots and lots of resource and advice and information.

ZS

Absolutely.

CB Lots of support, what Zoe has already said. I guess the last question then is if anybody who is listening at the moment thinks that they have an eating disorder, what would you say to them?

ZS

You're not alone. There's a whole community of people who are struggling and if you ever feel ready to talk to people who are also struggling, Beat Support Services are available. They've got a helpline, and they've got multiple chat services.

00:48:59

So, rather than just going into a room full of people with all sorts of different eating disorders and experiences, you can actually match up to a chat service that feels more

relevant to what you might be struggling with. For example, there's a chat service specifically for binge eating disorder. There's a chat service specifically, I think, for carers, which is also beneficial.

Definitely have a look at their website and explore their support services. You can be completely anonymous in that scenario as well but it does mean that you've got the opportunity to talk to people who might have shared experiences and that can feel really powerful and make you feel that you're not completely isolated in your experience. Also, don't even put yourself down thinking that you might not be sick enough to get help. You deserve help. You deserve to protect and really free your mental health.

You deserve to be free. I think a lot of people who struggle with disordered eating, they can be very functional. They can get by and still be doing well in their jobs and have really good relationships but one thing I would say is if you feel that way, oh, well, my eating disorder is something I don't want to get rid of, I don't want to recover, obviously you have total autonomy over your own body and your own mental health but having felt like that myself and now recovered, it's so worthwhile and it's totally possible is the other key message that I want to share. It's totally possible for you.

It felt so, so, so far beyond the limits of my capability at first and felt like it was just never going to happen and now I am in a totally different place. So, yes, to end on a positive note, it's totally possible for you.

CB

I'll pick up on the word that you used, freeing. You will be freed with your mental health, which must just feel fantastic.

00:50:43

ZS

Yes, it really does. You have room for other things in your life. When you're not totally obsessed with food and your body, you actually have mental bandwidth to do loads of other stuff and perceive loads of other hobbies and be more creative and be more present with your family and given that food is such an important part of our culture as well, you can actually enjoy social celebrations and gatherings.

I know it probably sounds really scary, the whole concept of going through the recovery process, and it's certainly not easy, it's not linear and it's different for everybody. I think it's particularly harder, I should definitely acknowledge, for people in larger bodies because we do live in a society that generally makes it much harder for people in larger bodies, especially with regards to things like commenting on food choices and societal standards and there's a whole other conversation I could bring to the table about that but I know we haven't really got time.

But even if you feel like it's completely unachievable, it is possible for you. I know people who've had eating disorders for 10, 20 years who've had all sorts of barriers and

challenges to their recovery who are also, some of them, in larger bodies as well, and they have recovered. It's totally possible.

00:51:53

CB

Fantastic. Thank you so much, Zoe. Thanks so much for your wisdom and sharing your lived experience.

ZS

You're welcome, it's really good to chat with 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 Hidden Disabilities Sunflower. You can also follow and subscribe to The Sunflower Conversations podcast.

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