

Avoidant/Restrictive Food Intake Disorder (ARFID)

Diagnostic Criteria

1. Avoidance or restriction of food intake that results in either, or both, of the following:
 - a. The intake of an insufficient quantity, or variety, of food to meet adequate energy or nutritional requirements
 - b. Significant impairment in functioning (e.g. due to avoidance or distress related to participating in social experiences involving eating)
2. Eating behaviour not motivated by preoccupation with body weight or shape

NB: Eating behaviour, weight or other physical health impact are not due to unavailability of food, a medical or mental condition, or the effects of a substance or medication.

(Based on ICD-11)

“ My daughter developed ARFID following a throat infection of already enlarged tonsils. At some point fear took over from pain and she was convinced that she would choke and die if she swallowed any food

at all. She lost weight dramatically and the impact this starvation had on her brain and body was scary. Trying to get someone to listen and understand the seriousness of the situation was frustrating. I felt that the situation was being minimized, that the impact of the starvation was being overlooked, and that I was just an overanxious mother. As an eating disorder clinician myself, I couldn't understand why our situation was not being prioritized in the same way as someone with anorexia. Different cause for the fear of eating, but same impact on the body and brain. Just as serious, and just as devastating. We eventually got support and she is thankfully now recovered.

Anita Jones, a mother

Introduction

Dr Eva Trujillo

Eva María Trujillo Chi Vacuán, MD, FAED, CEDS, Fiaedp, FAAP, is Executive Director and Co-founder of Comenzar de Nuevo, A.C., a Mexican-based facility specializing in the treatment, education, prevention and research of eating disorders. She is a Clinical Professor of Paediatrics at the Tecnológico de Monterrey, Escuela de Medicina y Ciencias de la Salud. She is the Founder of Habilita A.C., a national non-profit organization dedicated to supporting carers and families affected by eating disorders. She has held many advisory and board roles, and authored extensively on eating disorders and adolescence. She has given more than 350 conferences and workshops on these topics worldwide, receiving numerous awards and recognitions for her world-leading work. @etrujilloch

‘**N**ow everything makes sense to me.’ This is the most common statement I hear from our patients and families when I explain their ARFID diagnosis and how we need to approach it.

I have been in the field of eating disorders for a quarter of a century and, as a paediatrician, I get to talk to many parents of children, adolescents and young adults with food issues. For many years, one regular observation in clinical practice was that many patients with restrictive eating disorders did not fulfil the criteria for anorexia nervosa as described in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). They showed no fear of gaining weight, and often their reason for consultation was for this very reason – help to gain weight. Unfortunately, on many occasions, clinicians failed to help. Some dismissed any eating disorder diagnosis because patients had a

'normal' weight or were able to eat a lot of carbohydrates. Those of us who have been working with patients for a long time know that the big, grey area between normal eating and an eating disorder diagnosis is often full of suffering, pain and hopelessness for many people.

In Mexico, where I live, about 25 per cent of adolescents are affected by a mental health problem, and, unfortunately, less than 50 per cent of those will get the correct mental health support. In most Latin American countries, economic resources are very limited, and mental health services are usually not integrated into primary care services; less than 30 per cent of primary care services will have a treatment protocol for mental health issues. With all that said, the diagnosis of ARFID is often a real challenge.

Most families and patients affirm that they have been navigating a world full of mishearing, misunderstanding and misdiagnosing. Our patients have been easily dismissed as picky eaters or treated inappropriately as patients with anorexia nervosa. ARFID is not really a new diagnosis; it has existed for decades, maybe more, and has gone unrecognized for much of this time. This is why in 2013 – when the latest publication of the American Psychiatric Association's DSM (fifth edition) named and described a syndrome that reflected what many of our patients had been struggling with for years – many of us welcomed this change with open arms: a change desperately needed in our field. Even better, a few years later, Dr Jennifer Thomas and Dr Kamryn Eddy developed a therapeutic approach (cognitive-behavioural therapy for avoidant/restrictive food intake disorder (CBT-AR)) based on their research and clinical evidence, which helped us give hope to our patients. Other tools have been researched by others, too. We can now tell our patients that we have evidence-based solutions, and we have been adapting these to the Latin community. So far, we know that this syndrome is not culture-bound (limited to any specific society or culture).

ARFID is still not totally understood, and our field needs to work in the coming decades on research, treatment innovations and

sub-represented populations. We still hear professionals who have never heard of ARFID. It is imperative that we translate the research literature into an accessible and authoritative resource for those who suffer from this illness, their families, friends, loved ones, health professionals, educators and the public. I hope that we can bridge the gap between this urgent problem that affects too many people – children, adolescents and adults – and what we know about it. Bringing ARFID to light is the first big step towards helping patients, carers and professionals be seen and heard, and feel accompanied.

When Finding Food Is Like Finding a Needle in a Haystack

Sam Layton

Sam Layton is a mental health advocate and instructor based in North East England. By utilizing public speaking and social media, she shares her experiences of depression and avoidant/restrictive food intake disorder (ARFID) in the hope of reducing the stigma surrounding mental illness. She has a community of more than 30,000 followers across social channels. She is in the process of setting up a charity which aims to improve accessibility to services and provide resources for young people so that they feel they have the knowledge and support that they need. @samlaytonuk

If you tried biting into a block of plastic that had been coated in poison, you would struggle. The texture of the plastic would make it hard to bite through and the worry of the poison would occupy your mind, preventing you from putting any more in your mouth. That is what eating food can feel like to me.

For as long as I can remember, eating has been an issue for me. Whilst I don't personally remember much about the eating difficulties I had as a child, I've had many reminders over the years: family members mentioning how I would refuse to eat as a child, remembering how I would only eat one thing when having lunch at school, or reading through my medical history.

From the day solids were introduced into my diet, I struggled to eat. As a child, I opted to consume large amounts of liquid instead. So

much so that I had to be held back a year in school due to frequently going to the toilet. On the occasion that I *did* eat, I didn't eat much.

As a child, I ate tuna sandwiches, custard and a specific brand of cereal. That was pretty much it. And if the cafeteria ran out of the sandwiches I liked, I would happily not eat for the rest of the day. Some say that if a parent doesn't cave in to a child's wants, they'll start eating what they're given. For those like myself, diagnosed with avoidant/restrictive food intake disorder (ARFID), this is far from true. There was a mental block preventing me from eating food that I wouldn't usually eat. Still, today, the list of foods I *do* eat – which I call my safe foods – is much shorter than I would like it to be.

If I had a pound for every time someone gave me unhelpful information, I could buy a mansion:

'Just try new foods.'

'Remove all the foods you normally eat, and you'll be forced to eat a wider variety.'

'Hide the food amongst other foods to make you eat it.'

The list is endless. Whilst many of these may work for picky eating, it doesn't if the issues you're experiencing are a little deeper. If you bribed a fussy eater who refused to eat their bowl of salad with tickets to Disneyland, I'm sure they would cave and eat it. For somebody with ARFID, it's a completely different story. As a child, no bribe would make me eat.

As I got older, to force myself to eat a food I wouldn't normally eat, I would subconsciously try to convince myself that it wasn't food. Some argue that if you do this daily for a prolonged period, the said food will become a safe food. This wasn't the case for me. If I forced myself to eat a food, even if it was one I usually ate but for some reason I'd been slightly put off by it, I would lose my appetite. If this

continued for a period of time – where I forced myself to eat a food in the hope of overcoming my barriers surrounding eating it – my barriers would get worse. Rather than getting used to eating the food, I'd convince myself that I had to eat it. So every time I tried to eat the food, I'd lose my appetite, and a simple task of eating would turn into a mammoth mental struggle. This then led to an endless cycle of rarely trying new foods, even though my options were limited.

Over the years, in my travels across the world, finding food has felt like finding a needle in a haystack. In supermarkets the size of a football pitch, I'd find very few foods to eat. When abroad, there would often be nothing I could manage. Despite my family being Palestinian and Pakistani, even when I've been to those countries, it's still a challenge to find food I eat. The same goes for countries like Spain or the Netherlands, where supermarkets are similar to the UK. I'd walk down the sandwich aisle and see tuna and sweetcorn or ham and egg sandwiches. But, argh, why couldn't they have tuna and mayonnaise, or a sandwich with just ham!? I'd walk down the snacks aisle and look at the variety of items on offer: chocolate bars, biscuits, crisps and marshmallows. Nothing. Couldn't eat them. After searching far and wide, I'd finally find something I could eat, but it wouldn't necessarily be the same brand that I was used to. Or maybe the food looked different. All of these were barriers. I often relied on fast food when abroad and then struggled when in a city that didn't have a fast-food restaurant that I was used to eating from.

My inability to have a varied diet was made worse by my inability to taste properly. When I inhale through my nose, all I feel is the air going into my nose and through to my lungs. I can't smell the roses when taking a walk through the park, or the smell of the freshly baked bread when walking past a bakery. That's not because of any virus or allergy; I was born that way. Whilst there's no physical cause for it, it's something many have – congenital anosmia. Whilst not having the sense of smell in and of itself doesn't bother me, the problems it's led to, and continues to lead to, when it comes to eating, do. My lack of

smell results in me being unable to taste the cheese on the Margherita pizza I bought for lunch, or the chocolate in the chocolate croissants I snack on throughout the day. Whilst there are some tastes I can taste, these are few and far between. Whether or not I enjoy a food mainly depends on the texture. Sometimes the texture's just right and I'll happily devour a sharer pack of it.

A safe food I frequently eat is croissants with chocolate sauce inside. You know the ones. I really like those. Another product, by the same brand, has chocolate *and* vanilla sauce inside. The difference for most people would be the flavour. For me? The colour. Over the years, I've struggled to get over this block preventing me eating the chocolate and vanilla. I would eat it five times slower than normal, and with every bite I took, my mind would convince me that what I was eating wasn't nice. And if I couldn't find the brand of croissant I liked, I'd either struggle to eat other brands, or flat-out refuse. There may have been little to no difference. Or there may have been a big difference. But the difference was always the texture, as opposed to the taste. I often question how many of those differences were real and how many were psychological.

A commonly misunderstood experience for people with ARFID is the inability to have set meals each day. Whilst this may not affect everybody, I'm one of many who has struggled to have three set meals per day. When I was younger, I remember not being hungry, even for meals. Whilst I don't remember if I skipped meals or not, I remember that if given the choice, I could easily have done so. But when I *did* have meals, I would often snack. When I started expanding my diet to include certain sweets and chocolate, I ended up snacking throughout the day. This, in turn, led to me always being hungry. By the age of 15, if I was in school, I was unable to go even a few hours without having a snack. During multiple lessons throughout the day, I would *have* to have snacks. I got in trouble a fair amount because of it. Now, throughout the day, I can eat around half a dozen sandwiches. Other days, it may look different. I may just buy a large amount of fast

food – specifically nuggets and plain burgers – and consume them slowly throughout the day. One burger can take me five minutes to eat if I'm really hungry; normally, it takes about ten minutes, though. Sometimes, I can be eating the same burger for an hour. Whilst this causes problems in my current office-based job, it's thankfully not a major issue. In other jobs, though, I can easily see this being a problem. And it's a fear for when I'm job-hunting in the future.

Are my issues with food something I'd like to continue changing? Definitely. Do I think it's ever going to be easy? Sadly not. Many people in my life think I'm not changing quickly enough because I haven't acknowledged the health issues this has caused – and will continue to cause. Many think it's because I simply like relying on sweets and fast food that I frequently consume. Others think it's because I allow myself to have access to my safe foods and that simply restricting my access to them will force me to eat normally. This is far from the truth. I believe in taking manageable steps. First things first: to cope with my diet. Currently, my diet doesn't cause me any stress throughout the day. It's not something that crosses my mind most days. I'm able to eat in public without worrying what people would think of me if they were to see the difficulties I'd be experiencing otherwise. As a result of not stressing myself out with food, I can focus my attention on other aspects of my life too. This foundation makes it easier to move towards recovery and make those small forward-focused changes.

Accepting that this is not something that will disappear overnight allows me to be able to live my life like anybody else.