

Lived experience perspectives

Why we need this Guideline

Jo Farmer – lived experience advocate and Guideline Development Group member

“In hindsight, I’ve lived with disordered eating since I was a child. It emerged following some traumatic experiences, but my eating disorder wasn’t first identified until I was 19 years old and presented at my GP in the UK for treatment for another mental illness. At that time, the eating disorder services in my area only accepted people with a low body mass index (BMI). Since moving to Australia at age 21, it’s been a long journey of trying to access appropriate treatment, with periods where I’ve been well and managing, and several periods when I’ve relapsed. Currently, at age 32, I’d say I’m mostly well, but I still have periods where I binge, and others where I restrict ‘to compensate’, and food and eating remains something I’m hyper-vigilant about.

I feel very privileged to have been able to contribute to the development of this treatment guideline. For much of my recovery, I feel like I have been doing it alone, as I have struggled to access compassionate, equitable and effective treatment options for my eating disorder, as it presents in my higher weight body.

The most significant help I have received is access to high quality, trauma-informed psychological support. For so long, I believed – and others fed my belief – that my body was the way it was because of some inherent failure on my part. I’ve lost count of the number of times I’ve simply been told to ‘eat less, and exercise more’ (including by mental health professionals). That was never going to work for me – I needed psychological support that helped me to understand why I eat the way I do, and to provide me with other coping mechanisms when I need them.

Holistic care has also been central to this – health professionals across the range of services that I have accessed who understand my needs as a person with an eating disorder, whatever my weight. That means, a GP who understands that my eating disorder has prompted nutritional deficiencies, and treats them compassionately alongside my mental health needs, and a personal trainer who has taught me to love exercise for the way it makes me feel, not as a punishment.

But along the way, I have also experienced a lot of bad care. Health professionals who have made me feel ashamed for my weight and dismissed my concerns because I don’t look like the stereotypical eating disorder patient. They have frequently centred my weight and weight loss as the primary goal for my health – as though I wasn’t aware I was living at a higher weight! I’ve experienced a range of treatment from dismissive to outright discriminatory.

Far from helping me recover, this care makes me feel worse about myself, usually leading to a worsening of my mental health (and often weight gain). I hope this guideline demonstrate the pernicious effects of weight stigma, right down to the language we use to describe eating disorders as they present

in higher weight as somehow different from the same condition at a low weight (e.g., 'atypical anorexia nervosa'). Everyone is deserving of equitable care, regardless of what their body looks like.

Earlier identification and access to support likely also would have helped my recovery. My eating was viewed primarily as a weight issue by me, my family and health professionals, which got me caught in a spiral of thinking I was never good enough. Support and education for family members would also have helped to communicate what was happening with me and why. There is still a perception that people with eating disorders are thin, young, white women. If you don't fit into this body type, care can be dismissive, and there is an absence of culturally appropriate treatments and supports.

While I've experienced some very bad treatment, some has been good, too. This gives me hope that there's a future for eating disorder treatment without the stigma. I hope too that this guideline showcase the positive and proactive approaches to the treatment and support that works."

Zoe Bower, lived experience advocate

"I grew up chubby and as I entered adolescence and adulthood that became 'overweight' and then 'obese'. I have a few physical health issues that caused me pain and discomfort and I was told that losing weight would help and I should eat smaller portions and try to exercise more.

The first time I got this advice I was 10 years old. At age 10, I was told by my doctor that no one would ever love me at my current weight and that following his advice would make me healthier and happier. I followed this advice but never lost weight, so I was repeatedly doubted by many different medical professionals, so they repeated their advice. I missed out on a lot of typical teenage experiences by being at the gym and avoiding situations where I'd have to eat with people.

My eating disorder wasn't identified until I was admitted to an inpatient mental health unit at aged 20 but at the time, I wasn't in a place to treat it as depression and anxiety took priority. It took a few years before I was ready to get treatment for it, and I addressed it with my psychologist of the time. I was told advice that over the course of my life I have become very familiar with, eat less and exercise more. If I lost weight, then there'd be less fuelling the issues behind my disordered eating. Or at least that's how it was explained to me.

It took me some time to find a medical team I could feel comfortable with because even after explaining that I had an eating disorder, doctors would still tell me how much easier and better things would be if I lost weight. After 18 years and lots of support from family and medical professionals from various disciplines, I've stopped trying to lose weight and am focusing on healing my disordered relationship with food.

As I get older and my friends and family start having children, I've been worried that they will end up in a similar situation to what happened to me. My hope for these Guidelines is that they teach people that eating disorders aren't just for certain body types and that they lead to better supports in place for this under-recognised group, that the young people in my life can get diagnosis and appropriate treatment no matter what they look like."

The importance of identification and assessment

Julia Quin, lived experience advocate and Guideline Development Group member

“My daughter’s eating disorder sneaked into our lives so quietly that we didn’t notice at first. She was 15 years old and during early puberty had gained an amount of weight that placed her into an ‘overweight’ BMI body. So, when she suggested she might try some ‘healthy eating’ we didn’t think that was a warning sign of anything more insidious.

Within six months, she had lost more than 20% of her body weight and her period had stopped. We were very concerned as she had withdrawn from her family, wasn’t her normal happy self and her behaviours and fears around food were not normal. Our first visit to the GP was the ‘sliding doors’ moment where an eating disorder should have been identified. Instead, she was weighed and we were told, ‘It’s fine, she’s still a normal BMI. Her body probably went into shock from the weight loss and if she maintains this weight then her period will return’. Of course, that was not the case, and it took another eight months before she finally received a diagnosis of atypical anorexia and formal treatment/refeeding began. I consider our family lucky in that despite the unacceptable delay in beginning treatment, my daughter is now fully recovered. My wish would be for families who present to their medical practitioner asking for help, to have their concerns taken seriously on Day 1.

My message to clinicians: An eating disorder cannot and should not be diagnosed by an arbitrary number on a scale ... be curious and ask more questions. Please learn as much as you can about eating disorders and continue to keep your knowledge up to date with new findings/studies. Question your own biases/understanding around weight vs health and learn about Health at Every Size. Learn how to identify an eating disorder and the best evidence treatment modalities available.

Eating disorders exist in all age groups, all body sizes, all genders, and all cultures. The full recovery rate from a restrictive eating disorder such as anorexia remains abysmally low so, early intervention and immediate action is key to helping as many people as possible recover and go on to fulfilling lives ... please learn how to be a part of the solution! For an adolescent sufferer, the carers/parents are key to doing the hard work of refeeding at home so learn how to support and empower them – this is hard work for everyone, but the rewards are huge.”

Cultural considerations for the identification and treatment of eating disorders

AJ Williams-Tchen, lived experience advocate and Guideline Development Group member

“It started when I was in high school. I was 15. I was not coping at home. I was not coping at school. My fixation with food intake or lack of it, was something that I could control. After passing out a number of times, I was tested for everything from diabetes to possible brain tumours. The doctors just kept saying that they could not find anything wrong with me.

Throughout this time, I had body maintenance and being male, no-one could acknowledge or diagnose that I had an eating disorder. In Year 10, after collapsing in the playground at lunch, I was transferred to hospital by ambulance. It was a teacher that escorted me in the ambulance that made a comment to the paramedics that she thought I may be experiencing an eating disorder.

At the hospital things started to change. I was not poked and prodded at, rather the doctors and nurses started talking to me about my thoughts, feelings and experiences. I was diagnosed with bulimia. I was given the label - but no-one really knew how to work with me. 'I never worked with a male before', 'it is not common in boys', and 'you don't meet the case studies that I have seen in research' were common statements that the medical staff and allied health professionals like psychologists and social workers stated to me.

The health workers struggled at times to engage with me. I already felt odd and out of place and then to be told that I was an 'anomaly' was so hard. I remember being given a booklet about eating disorders. I could not see anything in it that related to me. It told me that my periods would stop, and my breast development would be disrupted. Everything that a 16-year-old boy needs to be aware of. Being an Aboriginal male there was also very little information about eating disorders in community or any real cultural support offered. I am not sure that much has changed over the last 30 years.

What I would like to see in the future is more recognition that eating disorders affect all people and is predominant in all cultures. It is important for young men to understand that eating disorders can affect them and to have resources and support tailored to meet their unique needs. It is also pertinent that health professionals work in culturally safe ways to support Aboriginal & Torres Strait Islander people and their families throughout their diagnosis and treatment journey.

So for me there were at least four assumptions that were wrongly made that prevented me from getting help earlier. Firstly, it was about who has or can develop an eating disorder. The second was that that health professionals were looking for a certain body size. Thirdly, there was a cultural barrier, nothing that was Aboriginal-specific as a resource and lack of cultural awareness or cultural competence. Finally, there was also a gender barrier that involved both the fact the professionals that I worked with mostly non-Indigenous females and I was a young Aboriginal male who didn't meet the stereotypes of those with an eating disorder, as well as literature that aimed for female clients. It is now time to make changes to stereotypes and becoming more culturally alert to the diverse range of clients. "