



# BEYOND STEREOTYPES

A lived experience guide to navigating  
support for disordered eating



East London  
NHS Foundation Trust

# A NOTE ON THIS GUIDE

*This guide has been **designed by ‘experts by experience’** in disordered eating. It is intended to be an informative and reflective space for individual experiences to be shared, and as **a welcoming non-clinical resource for those who feel they may be experiencing disordered eating**. These accounts come from people with a range of backgrounds, diagnoses, and experiences with therapy. They are intended to illustrate **what the process of recovery can look like for different people from the perspective of personal experience**, rather than as professional advice.*

*While we hope this may help you to make sense of your own experiences, everyone is different and what may be true for one person, may not be for another. Regardless of how much you resonate with the stories below, **you are equally deserving of support and recovery**. If you have any feedback on the guide, you are welcome to contact us at [elft.disordereatingsupport@nhs.net](mailto:elft.disordereatingsupport@nhs.net)*

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# INTRODUCTION



Disordered eating **can affect anyone, but it can be confusing to understand and recognise** it in our own personal experiences. Perhaps you are not quite sure what ‘disordered eating’ is, but you know that something feels wrong. Perhaps you recognise many eating disorder symptoms in yourself, but worry you are ‘not sick enough’ to deserve help. Maybe you’ve asked for help before but not received it, or you’ve previously had treatment and are wondering whether to try again.

Even after being referred to specialist services, **many of us continue to feel full of uncertainty** while on the waiting list – will anyone understand us? What will they think?

This guide is a **snapshot of how adults in East London have navigated those experiences of uncertainty** while seeking support for disordered eating. For many of us, preconceptions about what an eating disorder is (or isn’t) have previously acted as a barrier to seeking or receiving support.

We hope that our reflections will empower you to believe that **beyond the numbers and the clinical definitions, you are a complex human being who deserves to be seen as your full self**. Whatever your situation, there is no such thing as ‘not sick enough’ to deserve a life without the distress of disordered eating.

East London Disordered Eating  
Expert by Experience Group



# BEYOND THE STEREOTYPES

## About disordered eating

If you are experiencing **emotional and psychological distress around food and eating** in a way that is significantly impacting your life, you might have already recognised yourself as one of the 1.25 million people in the UK struggling with an eating disorder [1].

For many of us, though, **common stereotypes can get in the way, leading us to some version of the thought that “people with eating disorders don’t look like me”**. Maybe we think we’re not the ‘right’ size, age, ethnicity or gender, or maybe our symptoms don’t seem like they fit in one diagnostic box.

But **eating disorders don’t have a ‘look’; they are complex mental health conditions which may or may not have physical consequences, and they can affect anyone**. The term ‘disordered eating’ can also be a helpful way to describe experiences of distress around our relationship to food, encompassing a range of difficulties which may or may not fit a specific ‘eating disorder’ diagnosis. We will use these two terms interchangeably in our stories below, in which we explore our experiences ‘beyond the stereotypes’.

<sup>1</sup> <https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/how-many-people-eating-disorder-uk/>

# Personal stories

## Eating disorders, identity and culture

As a South Asian woman, I didn't understand my eating disorder for a long time. My immediate family and friends didn't have any awareness of eating disorders and I struggled to get help and support. What started off as disordered eating habits in my early years very quickly manifested itself as anorexia nervosa; all the while, I was becoming invisible. When I finally approached my GP, things had got quite bad. How I wish my mom, sister or even best friend had reached out to me.

Growing up I struggled with 'traditional' food, but eating it was a sign of respect in my culture. I think my food fears started when I felt too afraid to complain about the food - instead, I started reducing my intake.

As a young woman, my slender weight was celebrated as it meant I would be more appealing for marriage. Within my friendship circles I was known as the 'thinnest';



**“I had finally found an identity for myself, after years of being invisible.”**

finally I had found an identity for myself, I was known for something after years of being almost invisible. Desperate to live up to my new identity, my eating disorder spiralled out of control. Fast forward several years, post marriage and kids, and I found myself finally seeking professional support. At first, I struggled with specialist services, feeling I didn't fit in with the 'stereotypical' eating disorder sufferer. It felt like there wasn't space for my personal identity and I ended up being re-referred three times. But after a while I found therapists who understood my identity and the

ways in which this influenced my triggers and fears - they were the help I had desperately been seeking.

Now, I experience something I had never imagined possible: my children are my biggest supporters. I call them my cheerleaders - they are fully aware of my eating disorder and support my recovery journey as a family. It turns out that help comes in many forms, shapes and sizes. Never lose focus on your end goal; perhaps some doors you tried did not open, but eventually one will lead you to the right path.

## Seeking help before 'rock bottom'

I waited for a long time before mustering the courage to contact the NHS and ask for support. I come from a culture where the norm is to power through problems. Unless they're significantly impacting your life or that of those around you in an obvious way, you don't want to inconvenience anyone by discussing them. I've always believed that I wasn't 'sick enough' to ask for help, fearing

that I might be taking someone else's spot, someone who might genuinely need it. After all, I could go to work. I could enjoy time with my friends. My body wasn't falling apart, and the physical consequences of my ED

**“My body wasn't  
falling apart –  
maybe I'd get used  
to it.”**

would take a while before becoming evident or disruptive. Never mind the consequences on my mental health: as long as I could function and organise my illness around the life I was supposed to be living, I was sure I could just carry on and maybe the problem would go away on its own, or maybe I'd get used to it, or maybe, maybe, maybe...

The moment I reached out for help was one of the proudest in my life. I felt that, at last, I was taking action and protecting myself from more inevitable hurt. Up until that moment, I considered it a defeat. I'm not actually *that* sick. Others have it much worse. I can still cope. No one really notices, so it's probably not something that I should bother fixing. Over time, I realised that I didn't need to hit rock bottom to ask for help.



My disorder didn't need to become fatal for me to do something about it. You can get better before reaching your 'worst'.

## Parenting with an eating disorder

For me, parenthood has been entwined with both hope and challenge. Several years prior to becoming a mother I had developed an eating disorder, turning to exercise and calorie control in search for relief from severe anxiety and depression. However, with the hope of one day having children - and the help of treatment - my life changed course. In a few years I went from the depths of despair to happily married and pregnant.

During my pregnancy I fell back into depression, fuelled by unrelenting nausea, isolation, and unemployment. In an effort to manage my emotions, I returned to exercise and calorie control. My drive to exercise was also driven by a fear of 'letting myself go' and having a 'post baby body'. Whilst I didn't feel the same despair as I had the first time I was diagnosed with an eating disorder, I wasn't sure I was okay and decided to say something to my midwife – I'm so glad I did.

Shortly after my daughter was born I began to get some help from a perinatal mental health team. I wasn't sure I deserved their support, but felt our monthly 'check in' sessions were enabling my little family to 'keep our heads above the water'.

**“My identity as ‘mummy’  
brought new  
opportunities for  
recovery.”**

When I later returned to eating disorder treatment, I felt my identity as a mother was not understood and I left feeling like a failure – but fortunately the story doesn't end there.



I began making artwork about my experience of motherhood and mental health. The intensity, the trials, the challenges and the failures – but also the new opportunities for recovery brought about by my identity as ‘mummy’. By trying to teach my daughter a healthy relationship with food, I am able to see more clearly what this would look like for me. And as things have improved, I have reached out again for eating disorder treatment. Finally, I think I have found professionals who seem to understand all parts of my identity.

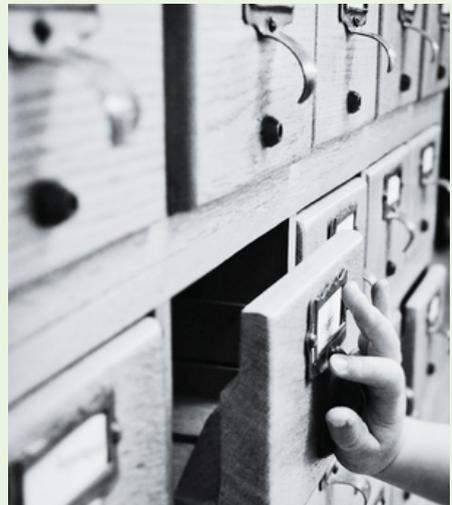
## Struggling at a ‘normal weight’

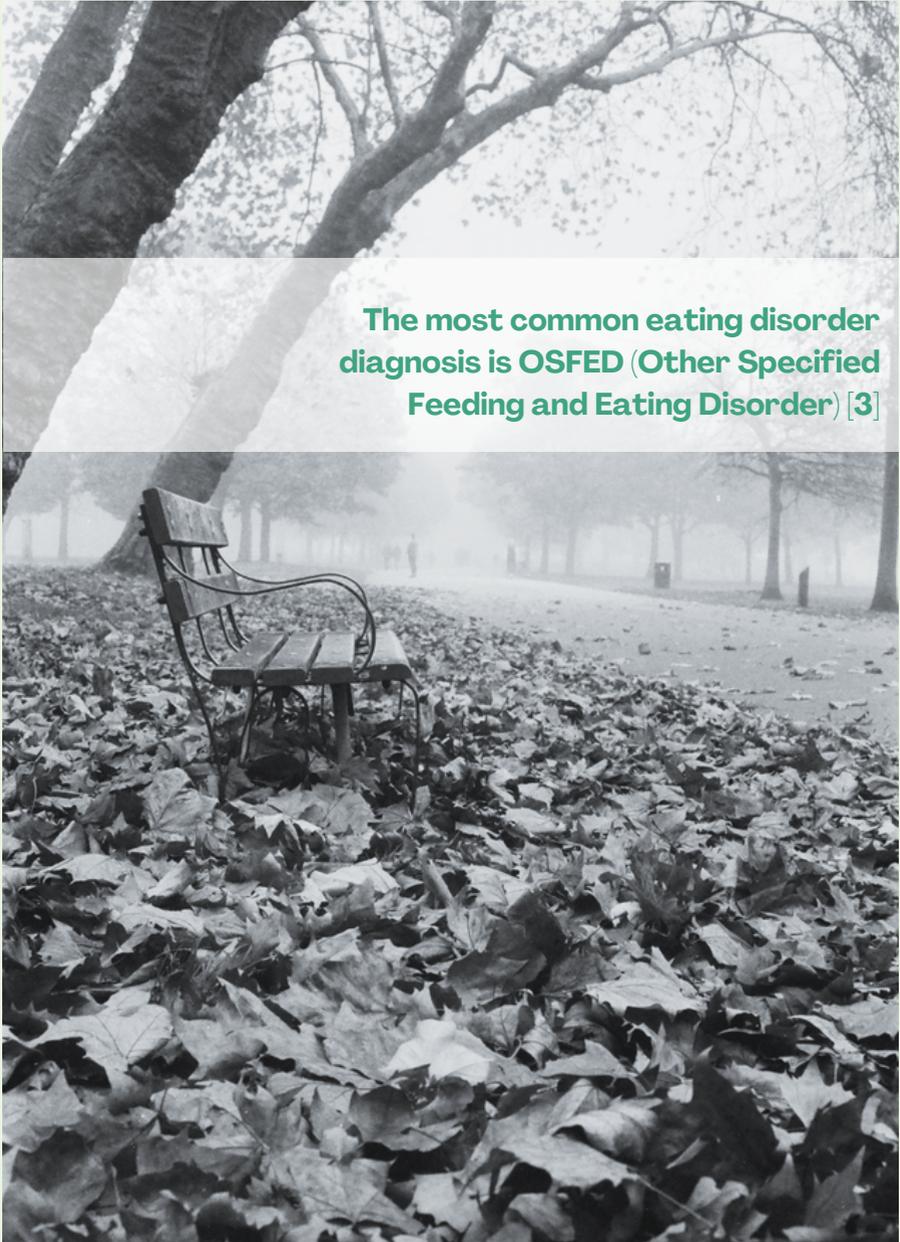
When I first presented to an eating disorder service back in my hometown, I was in the clutches of a horrific disordered eating cycle that felt absolutely terrifying. It took every ounce of my resolve to self-refer to the community eating disorder services. I was very, very mentally unwell. Yet, when I attended my first appointment, my assessor weighed me, glanced at the number on the scales, and declared ‘you’re fine!’.

**94% of people with eating disorders are not clinically underweight [2]**

Predictably, I went home, sobbed on my bed for hours, and then spiralled, thinking that the only way to prove I was ‘ill enough’ was to look the part. Only at my follow-up appointment was my deterioration taken seriously, because I had entered the underweight BMI category. Luckily, systems have been improving since I first self-referred, and I definitely don’t want my story scaring anyone off from accessing the support they need and deserve.

But the belief that eating disorder severity correlates perfectly with weight loss is still rife in society as a whole, so I still feel the need to use my experience as a reminder for anyone who needs to hear it: weight alone is not an acceptable way of measuring how ‘fine’ someone with an eating disorder is. Eating disorders are mental illnesses. The majority of people with eating disorders are not clinically underweight. You do not need to ‘prove’ that you are suffering through a number on the scales - you know if you are suffering, and that is enough. You deserve help and support, no matter your weight.





**The most common eating disorder diagnosis is OSFED (Other Specified Feeding and Eating Disorder) [3]**

<sup>3</sup> [https://www.beateatingdisorders.org.uk/media-centre/eating-disorder-statistics/#:~:text=A%202017%20study%20by%20Hay,disorder%20\(OSFED\)%2047%25](https://www.beateatingdisorders.org.uk/media-centre/eating-disorder-statistics/#:~:text=A%202017%20study%20by%20Hay,disorder%20(OSFED)%2047%25) ]

## Autism and eating disorders

From a very, very young age, I felt like I was just inherently wrong. I found a lot about forming relationships and friendships quite baffling and there's a lot about basic living that I find really challenging to manage, even now as an adult. I struggle a lot with very intrusive thoughts about not being good enough, worrying that I'm getting things wrong and putting a lot of effort into 'masking' my true self to fit in.

**“My path to recovery needed to be a bit different to other people’s.”**

My eating disorder provided a feeling of escape from these overwhelming feelings, because it was very rule focused. As an autistic person, I found (and still find) a huge amount of comfort in the repetition of a behaviour or routine, so it was like creating my own little bubble of control in a world that feels very confusing and disorganized. At certain points it really did feel like anorexia was my friend alongside me in that inner world.



My autistic traits and experiences meant that my treatment needs and my path to recovery needed to be a bit different than other people's. There's still a lot of repetitiveness in my eating that might look disordered to others, but it's more flexible and comes from an autistic kind of comfort in repetition of certain sensory textures – it feels like a form of 'stimming' to self soothe. Equally, my eating disorder might have exacerbated feelings of isolation and disconnection, but it was actually a pre-existing challenge that I'd had since I was tiny – my anorexia had grown out of that feeling, rather than being the root cause of it.

Part of my recovery has been about coming to terms with the fact that I often still feel a bit like an outsider a lot of the time, but I'm more at peace with that now because I'm building a life of my own, filled with the things I want to do.



## Not fitting a specific diagnosis

I didn't really believe I had an eating disorder for years, because I had such a mix of different symptoms that didn't fall under any one label – I was worried that treatment 'wasn't for someone like me'. When I did get referred, I often felt like I was 'performing' a role rather than really being myself in sessions, to try and match what I thought they would expect of me. I felt like I didn't deserve help if I wasn't the 'perfect' eating disorder patient, so I ended up not sharing certain symptoms, behaviours and experiences that I thought 'belonged to a different diagnosis'.

I was afraid I would be disbelieved or discharged, fuelled by the constant fear that I 'wasn't sick enough' to say I had an eating disorder. I now know that it's incredibly common for people to experience a mix of behaviours, regardless of diagnosis.

**“I felt like I didn't deserve help if I wasn't the 'perfect' eating disorder patient.”**

For example, just because your diagnosis is a 'restrictive' one doesn't mean you might not also experience symptoms such as bingeing.

I've also learned that it's normal for someone's symptoms to shift and change, 'migrating' across different diagnoses over time and often not fitting into any specific diagnosis at all. This is why I think the term 'disordered eating' is so helpful: it allows us to express our experiences in all their complexity, and to validate our own struggles even if they don't seem 'textbook'. I wish I had known that the eating disorder professionals would have seen experiences like mine many times before, and that most people are not 'textbook'. I spent a lot of time trying to mould myself into a certain box before seeking help, but I know now that I already deserved support to recover just as I was.



## Feeling misunderstood as a man

I think there's a huge stereotype where people think eating disorders are only an issue for women, but it also happens for men. Rightly or wrongly, it's something that I've always grown up with, thinking that eating disorders are associated with women.

Maybe subconsciously that's why I've been quite resistant to conversations about it. I really got the bug for restriction and losing weight, I'd be doing it at will and I had to step back and say to myself ok, I think there might be a problem, because it's like I just wanted to keep going.

But whenever people did express concerns about my eating or my weight, I didn't want to hear it, I'd block it off.

**At least 25% of people with an eating disorder are male [4]**

I'd had some bad experiences with non-specialist healthcare professionals bringing it up in a way where I felt they didn't really understand what I was experiencing. One time I was at my mental health centre for a physical health check-up and the person who was examining me just blurted it out in a very insensitive way, about being underweight and telling me 'you need to eat these things'. He didn't take the time to ask what I was eating, what I couldn't eat and why, so it felt like I could only respond with frustration. He didn't have any suggestions for alternative things I could eat and I just got so angry that I ended up being very reluctant to talk about it to 'so-called healthcare professionals.'

People really need to take the time to ask us about our personal needs and situations in a sensitive way before telling us what to do, otherwise we can shut down. In a society where men often feel we 'have to be' quite well built and macho, I don't fit that stereotype as I'm not very tall and am very slim. It's quite a difficult thing for me to talk about and all these experiences and expectations have made things harder to come to terms with.

**“People think eating disorders are only an issue for women, but it also happens for men.”**

When it comes to men, it feels like eating disorders are seen as a non-existent issue and there's still such a lack of awareness that this is something that men can – and do – experience too. But there are lots of us out there, and we are equally as deserving of being understood by others.

<sup>4</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4538851/>

## Recovering with a chronic condition

I had started recovery for anorexia nervosa several years before the first symptoms of my physical health condition, Hypermobile Ehlers Danlos Syndrome (hEDS), began. Just before I was eventually diagnosed with hEDS, my symptoms of chronic pain and fatigue had accelerated, and many forms of exercise which had been an integral part of my post-anorexia life were no longer accessible to me.

**“My body – bendy, achey, faulty – is inherently worthy of care.”**

Disordered thoughts sprang up from the depths - should I be more 'cautious' with what I ate now? How else would I avoid putting on the weight a part of me still dreaded, given I was moving so much less? Wouldn't it be calming to regain some 'control' over my painful, tired body, a body which now felt so wildly beyond my control in every other way?

Wouldn't restriction provide a way for me to punish my defective shell for the pain it was causing me, or else a numbing distraction from the grief and uncertainty I felt about my new diagnosis? I found myself at a crossroads. While it was a wrench, ultimately, I didn't choose anorexia - in many ways, my resolve not to give in to disordered urges actually strengthened when I realised I had other health problems to contend with. On the other hand, my favourite pro-recovery mantra suddenly became entirely unhelpful. 'Focus on what your body can do, not what it looks like' is more triggering than it is comforting when you feel like your body can't do anything much without painful injury. I have had to accept that my body - bendy, achey, faulty - might just be inherently worthy of care regardless. If you're also grappling with other health problems alongside your eating disorder, I promise your body is worthy of that care, too.

## A caregiver's journey through systemic barriers

Embarking on the journey of caring for someone with disordered eating has been a roller coaster of emotions, challenges, and moments of profound connection. From subtle signs that raised concern to advocating within the healthcare system, this experience has underscored the importance of a holistic and culturally sensitive approach to care.

The journey began with skipped meals, obsessive calorie counting, and unease during mealtimes, as balancing support without intrusion became a delicate dance. As a caregiver, part of my role involved advocating for my loved one within the healthcare system: researching treatment options, attending medical appointments, and collaborating with professionals to secure the best care possible.

Being an older individual with significant language barriers presented us with additional challenges. Critical decisions about my loved one's treatment

often rested in the hands of others, leading to a sense of powerlessness. Navigating the healthcare system often felt like an uphill battle, especially in finding professionals attuned to our cultural context. I frequently found myself explaining cultural practices surrounding fasting, body image, food choices, and the unique meanings our culture attaches to mental health.

**“As carers we must also remember to prioritise our own wellbeing and recognise the power of open communication in fostering a supportive environment.”**

But this journey has also ignited a passion in me for advocating a holistic approach to care that respects individual differences, including cultural nuances. Above all, I want to emphasise the importance of healthcare professionals understanding and

integrating cultural practices into the treatment plan.

Witnessing the internal struggles, fear, and desire for control in my loved one was heart-wrenching, but together we were able to confront stigma and seek understanding from family and friends. This experience has highlighted the importance of empathy, compassion, and patience, not only from the caregiver but also from the individual facing disordered eating.

As carers we must also remember to prioritise our own wellbeing and recognise the power of open communication in fostering a supportive environment. By sharing our experiences, we can contribute to breaking down barriers, improving understanding, and ultimately creating a more compassionate and supportive healthcare system for individuals facing disordered eating.



# YOU'RE NOT ALONE IF YOU...

Don't have a formal diagnosis

Feel ashamed of opening up about your disorder

Feel stuck between wanting to get better and not knowing how to do it

Are not 'underweight'

Don't know what your identity would be without disordered eating

Feel like almost everyone has heard of eating disorders, but very few people actually understand them

Worry that you will lose 'value' if you recover

Don't relate to common stereotypes

Haven't lost or gained weight during your eating disorder

Know that something is wrong, but aren't sure if it 'counts'

Have an eating disorder that's not anorexia

Have struggled to find help that works for you

Have been denied support in the past

Have faced weight stigma

# RETHINKING RECOVERY

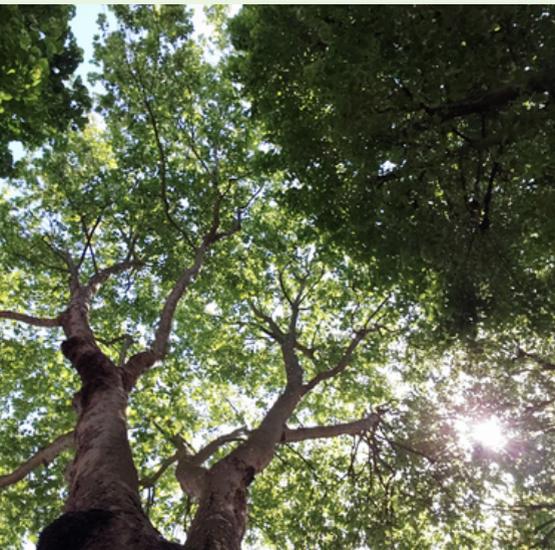
We hear the word ‘recovery’ all the time when talking about eating disorders, but what does it really mean? In our peer group we found that the word held different meanings for each of us, with one common thread: **for ‘recovery’ to be truly meaningful and relevant to our lives, it had to be something we defined for ourselves.** Some people feel like it’s a lifelong process, while others identify as ‘fully recovered’ after a finite period. We are all different people, living different



lives in different bodies – so **your recovery won’t look the same as my recovery, and you may not even choose to call it that at all.**

Along with the common factors and goals that many of us with eating disorders may have, **we are each living in our own unique contexts, with our own hopes, fears and motivators.** Treatment can be a tool for getting there, but no eating disorder professional or clinical definition can fully define what ‘recovery’ looks like for you. **You are allowed to set the terms of your own life.**

Below are a few of our own definitions of ‘recovery’, followed by some of the practical steps we’ve taken along the way.



# Recovery is...

## Not a binary concept

I don't view recovery as a binary concept, where you're either cured or you're not. You can relapse and still be recovered. Recovery to me means that **the struggle might go on, but I have the tools to counteract it and guide myself back onto the right path.**

To me, recovery feels like taking back control of how I feel. Yes, I might not always be able to follow a healthy pattern. But as long as I understand what is going on and why it's happening, and as long as I have the willingness and self-compassion to improve the situation, then I can't be too far off.

## Daring to imagine

For me, recovery has been about imagination. I used the scaffolding provided by professional treatment - and then I dared to imagine a life beyond it. **I gave myself permission to explore ideas in line with my own values** - ideas about food, bodies, politics, and life. I also gave myself permission to leave behind any tools or narratives that didn't work for me.

In other words, **I started to build a life that was truly mine by daring to imagine that I was worth more:** more than the 'eating disorder identity' of illness, and more than the 'paper self' of clinically defined recovery. Other people's definitions of recovery were a necessary stepping stone along the way to 'recovered', but they were never the 'full me'.

## Taking the mask off

Recovery is a personal journey, unique to your own values and identity. As a South Asian woman, my eating disorder wasn't understood by my family or my caregivers. But when I found therapists who were **able to see me as my full self, who allowed me to have a voice and lead on my recovery journey... suddenly, I was able to break free** from the shackles of my eating disorder, after believing I never would. Recovery to me is that feeling of finally being able to take the mask off: after so many years it felt surreal, but this process is the most real I've ever been.

## Life beyond treatment

I spent a lot of time in treatment, but my true recovery has been about what has happened in life outside of it. Clinicians were only one tiny part of the picture for me. I needed support to find my passion outside of the medical system, **to build an identity outside of my eating disorder. My life has expanded** and I feel a sense of value and purpose; it's been slow and it's been subtle, but it's been on my terms.

## A lifelong journey

When I committed to recovery for the first time, it felt like something with a finite start and end point - I used to say to people, 'I was in recovery, but now I'm recovered'. More recently, I see it as a lifelong journey. Life events, hormones, triggers, sleep, difficult emotions, and other circumstances mean that **sometimes it feels particularly hard to avoid disordered thoughts or behaviours - but this, to me, is all part of my recovery.** It's a very imperfect, rewarding, ongoing process of increasing self-awareness, self-compassion, and fulfilment.

# Full recovery is possible

For me, full recovery from anorexia means that I am no longer defined by it, I no longer hear it and I no longer see it. Also, that I don't need to explain my food choices or reassure others that "I know and I'm dealing with it". That shadow that was with me every minute of every hour of every day has finally left the building - not even Christmas triggers it anymore.

I remember being told "it will probably always be with you", which I found so unhelpful - because where is the hope in that? Still, I refused to accept it and was determined to find a way - even if I had to do it myself.

There are some things I will probably never eat and a level of spontaneity I will never have, but that's ok. For me, recovery isn't about being able to eat all the foods - it's about being able to feel all the feelings!

Now, I can laugh, cry and love with all my heart. It's painful, it's difficult and it's exhilarating - it's life, and I am so happy to be here for it!



# HOW WE FOUND OUR OWN PATH

## Being yourself in treatment



### Speaking up

I wish I'd known that I was “allowed” to say if certain aspects of treatment didn't feel relevant or helpful for me, or if I had a question about something that my therapist hadn't already raised. I followed everything like a student because I wanted to please them and was scared of getting it 'wrong'. Now I know that **it's completely normal for you to discuss questions and give honest feedback to therapists** - they can help you most effectively if they know what's really going on.

### Permission to go further

If there are parts of your treatment plan that start to feel limiting, or **you feel like you could challenge yourself more than your therapist is expecting, please don't hold yourself back**. For me, as someone recovering from a restrictive eating disorder, this meant things like giving myself permission to gain more weight than the 'target' minimum BMI I was given, and allowing myself to eat more than my meal plan once it

was medically safe to do so. **I was so ashamed of my hunger, especially when I had ‘extreme hunger’, but it’s really normal** and honouring it fully was such a turning point in my recovery.



## Staying authentic

I was almost ready to give up; I thought I would never recover from my eating disorder. After going through so many services - my GP, eating disorder treatment, community health and outreach services - **I still hadn't ‘recovered’. I thought I was unrepairable, broken for life.** In the end, all it took was for the right help to find me. In hindsight, it was me that helped me - I just needed to keep going. I never gave up on me, even though it felt like

recovery was unimaginable. I found services who trusted me, and **I was able to recover by staying authentic to the real me.** All the other times I had been pretending to be someone else. Is it any wonder I could not find recovery? Try just being you - and trust the process from there.

**“In hindsight, it was me that helped me”**

# Beyond treatment



## Peer support

Help can come from the most unexpected places. **Despite the expectation that ‘proper help’ is always clinical or therapeutic, sometimes all it takes is for someone to understand you.** Participating in ‘lived experience’ work locally helps me to feel a sense of community with other people who have ‘been there’ - and this helps me to stay on track with my own recovery.

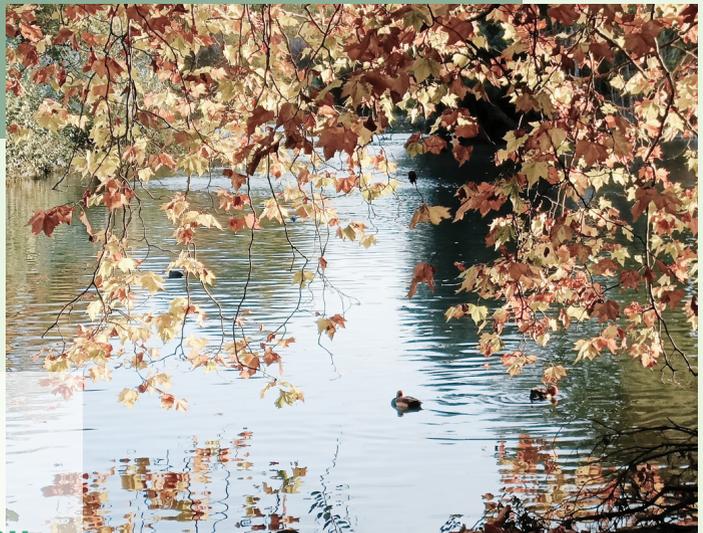
**“it transformed the way I see myself”**

## Practicing creativity

Kick starting a daily drawing habit was the game changer for me - **my pencils became the greatest recovery tools and my route back to living consciously, with free will.** For an hour a day I let my inner artist/child take over, and in that time the negative voices stopped - doing this day after day, month after month, year after year and they are no longer heard. Embracing my creativity helped me to ease out of the grips of anorexia after 16 years, and it completely transformed the way I live, see and feel about myself.

## Learning new ways of thinking

It felt so difficult to recover in a society that so often celebrates weight loss and moralizes food choices - everything felt triggering to me. Learning about concepts such as weight neutrality, fatphobia and Health at Every Size gave me a different framework for thinking about myself and the world around me - they helped me to challenge the 'triggered' feelings and keep pushing through. The process of unlearning weight stigma has been central to my long-term recovery and I see the world in a different way now.



**“I see the world in a different way now”**

# Coping strategies

## Visualisation



I have often tried to picture what my life would be like without my eating disorder, visualising **the things I would be able to experience and how unencumbered my daily routine would be**. Imagining in vivid detail what I'm missing out on and all the little joys I could have really helps me find inspiration and hope.

## New patterns

I find it helpful to **focus on my new eating habits rather than the old ones**. Building new patterns makes shedding the old ones easier and more natural.



## Opposite actions



Whenever I was experiencing anxiety or paralysis around food, **I would identify what my eating disorder was telling me to do** – e.g. ‘pick the lower calorie sandwich’. Then I’d **do the exact opposite**, i.e. pick the highest calorie option.

Other people’s actions will be specific to their own struggles, but the key is to **choose what the ‘disordered’ brain is most afraid of**. Over time, my repeated ‘opposite actions’ taught my brain that there was nothing to fear, and I stopped experiencing decision paralysis around food.

**“I taught my brain that there was nothing to fear”**

## Social media

Many 'recovery' accounts can perpetuate stereotypes, leaving us feeling like we are 'wrong' if we don't recover into a very thin body, or if we experience anything other than anorexia. But in reality, **we have no way of knowing if someone we see online truly has a healthy mindset.** In the end, I stopped looking at these accounts. Comparison used to make me feel so invalid, but now I know that you can't build your own life based on someone else's weight or meal plan.



## Self-compassion

I always felt like I had a storm brewing in my own mind, on edge and expecting the worst. I was full of negative thoughts and a rumbling belly that stopped being a feeling and became a habit I learned to manage. **I only learned how to cope with my emotions when I became attuned to my own physical feelings.** I practised compassion with myself; I stopped judging me.



Realising that my obsession with perfection had been my downfall, **I learned to let go and stop trying to perfect every single thing.** In the end, I accepted that nothing and no one is ever really perfect.

**"I practiced compassion with myself; I stopped judging me"**

## Rationalising

If I lapse, I try to take stock of the experience and analyse it from a rational perspective, leaving out the feelings involved and any sort of judgment. **I replace the fear of being out of control with curiosity about the feeling itself.** Once I rationalise it, it's easier to treat it as something disconnected and external, rather than something that is happening passively to me or that I am to blame for.



# On ‘deserving’

**\*Never\*** let your eating disorder, or anyone else, make you believe you’re ‘not sick enough’ to start trying to recover. Not everyone in the world understands disordered eating, but you yourself know if you’re feeling distress – so you know that it’s real.

I used to interpret everything as a sign of ‘not deserving’, including my experience of seeking support from mental health services. When I didn’t ask for years because I felt like I didn’t ‘look’ disordered enough; when I did ask for the first time, and the GP didn’t understand; when I found a GP who did understand and I had to spend time on a waiting list before I got treatment...



**“You are allowed to validate your own distress”**

Now I see that all of this was due to external factors – it was never a reflection of my worth as a person, or how ‘real’ my distress was, and it never meant I didn’t deserve to recover. You deserve professional help from services, but you do not have to give them the power to define how ‘valid’ your distress is. You are allowed to keep that power for yourself. You are allowed to validate your own distress.

# Every day is the right day

Don't try to walk someone else's journey,  
walk your own path

don't try and see from others' perspective,  
use your own sight

in a world full of copies be your own self

(it's ok to feel confused) -

it is never too early or too late

to ask for help, and

every day is the right day

to make a change you need



# PROFESSIONAL SUPPORT

## Asking for help

Hopefully, this guide has empowered you to feel that you deserve help and support if you are experiencing distress around food and eating. **You may wish to seek NHS support if you have not already done so – you can find information about how to do this on pages 32-34.**

While none of us regret seeking treatment and embarking on recovery, we recognise that we still have a long way to go with educating all healthcare professionals about the realities of disordered eating.

**“You know if you’re feeling distress, so you know that it’s real”**

If you are worried about coming up against stereotypes and ideas that may exclude you from being referred to the right support, **the eating disorder charity Beat has put together a [leaflet](#) that you may find helpful to bring to a GP appointment.** This includes guidance on how to respond to misconceptions and ask for a referral to specialist services. You can download a copy of the *GP Leaflet (First Steps)* [here](#).



# East London Foundation Trust

## East London Community Eating Disorder Service (Adults)

The East London Community Eating Disorder Service provides specialist, evidence-based treatment to adults struggling with eating disorders and disordered eating symptoms. The service offers outpatient therapeutic and dietetic support, and can also refer to eating disorder specialists in other services where appropriate. If you are aged 18+ and live (or have a GP) in the boroughs of Tower Hamlets, Newham, or City & Hackney, you can either:

- Complete a self-referral form yourself, or
- Ask your GP or health professional to make a referral using the form under the 'How to Refer' section of our website



Scan for self-referral

The self-referral form was co-produced with 'experts by experience' with the intention of making our service more accessible to people who may have faced barriers to asking for support in the past.

**“My therapist could not have been a better match for me...I will never again doubt the power of talking openly and honestly with a stranger.”**

# Bedfordshire and Luton Community Eating Disorder Service

Bedfordshire and Luton Community Eating Disorder Service (CEDS) is a specialist service working with adults aged 18+ who have a registered GP in Luton or Bedfordshire. **Our vision is to support people to a life worth living** and improve health for people in our population, via reduced eating disorder symptoms and distress, and improved functioning and safety.

As a service, we aim to provide assessment, support and therapy following NICE guidelines, and our multi-disciplinary team can provide psychiatric support and dietetic intervention alongside psychological therapy and medical monitoring. We also **work in partnership with local eating disorder charity Caraline** (see *below*), who offer treatment for eating disorders.

## How to refer

If you are struggling with food and eating and have a GP in **Bedfordshire or Luton**, you can **ask your GP to make a referral to us**. We also welcome referrals from CMHTs, IAPT services and from other statutory and non-statutory services, but we may ask these services to refer to us via a GP. Find out **more on our website [here](#)**.

## Caraline

Caraline is an established eating disorder charity providing evidence-based treatment to people aged 16+ and their carers. **We work in a stepped-care partnership with our Community Specialist Adult Eating Disorder Service (CEDS) and specialist Child and Adolescence Eating Disorder Service (CAMHS- CYPED) across Luton and Bedfordshire.** Services provided by

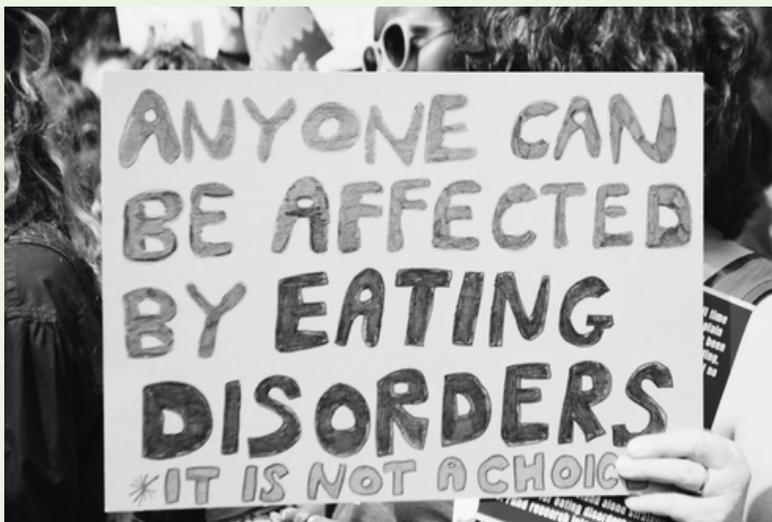
Caraline include a bi-weekly peer support and carers group, individual Enhanced Cognitive Behavioural Therapy (CBT-e), Cognitive Behavioural Therapy Ten (CBT-t), CBT ARFID (CBT-AR) and Eating Behaviour Group Therapy. We also deliver training sessions on disordered eating and eating disorders.

### How to refer

Self-referrals can be made to Caraline using the **referral form on our [website](#)**.

## NHS services in other areas

If you live in an area that is not served by ELFT, you can find information about **your local NHS eating disorder services by [using the Helpfinder](#)** search function provided by eating disorder charity Beat.



## Images

All image credits go to Lottie Bolster, an expert by experience and artist with a background in clinical neuroscience. Her work draws on personal experiences, both her own and others, to question common assumptions and stereotypes – particularly around eating disorders and motherhood. As an artist, she hopes to show how we can tell stories of disordered eating without images of people and bodies.

## Acknowledgements

This guide has been designed and co-produced by members of the East London Disordered Eating Expert by Experience (EbE) Group. The EbE group is based within the adult Community Eating Disorder Service at East London NHS Foundation Trust, where members use their personal lived experiences of disordered eating to contribute to the design and development of the service.

Thanks go to everyone from the group who has generously shared their ideas, experiences and design expertise for this project. Without your courage, honesty and creativity, this booklet would not be possible.

