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ORIGINAL ARTICLE

Frustrating the Recovery Narrative: Living Well with an Eating Disorder

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Abstract
This piece is based on an open discussion between five adults who have all experienced/continue to experience various forms of eating disorders. Here, they challenge the linear, progressive notion of recovery as a journey from being ill to being 'recovered'. Instead of a single narrative on recovery, the group hopes to make space for the multiplicity of different experiences, highlighting the notion of 'living well' with an eating disorder – a journey which involves re-building relationships with oneself and others, as well as with the eating disorder itself. By sharing this conversation, the group hopes to challenge the hierarchical notion where the expert voice is always given more value than lived experience, using their own words to craft a different way forward.

Keywords
experience of eating disorders, eating disorder recovery, eating disorder treatment, living well with an eating disorder, critical eating dis/order studies,

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Frustrating the Recovery Narrative: Living Well with an Eating Disorder

For decades, the way we understand and treat eating disorders has been primarily shaped through a biomedical lens. Access to NHS eating disorder services is dependent solely on whether a person meets criteria defined by psychiatry. If access is granted, there is little choice in the kind of treatment available, and a failure to 'progress' carries a risk of being labelled 'treatment resistant' or 'chronic', or simply being discharged. For those whose experiences do not match the predetermined ideas of psychiatry, there is subsequently little choice but to try and live well with their eating disorder. However, given that anorexia nervosa has the highest mortality rate of any psychiatric illness, there are many of us who do not make it.

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The main reason for wanting to share this conversation was to frustrate the dominant medicalised consensus on eating disorders, in order to present a more nuanced understanding of the recovery narrative. This conversation was not defined by any academic institution, nor shaped by criteria written by psychiatry and psychology. Instead, what is offered is an open conversation that centres on the lived experiences of five adults with eating disorders. In-keeping with survivor-led research, we wanted to provide a discussion on eating disorder recovery that is grounded in actual experience, instead of sanitised and thematically organised narratives written about us, rather than by us. Specifically, there are two questions that engage with the themes of this journal's special issue: *"What do you think about mainstream narratives of recovery?"* and "*What does living well with an eating disorder mean?"* We hope that presenting our discussion can encourage other survivors and mad researchers to join us in re-shaping the way we think about and treat eating disorders.

This discussion took place at Norton Park Conference Centre in Edinburgh, and was facilitated by a collective advocacy worker on the themes of recovery. The conversation was recorded, then individually transcribed by each participant, and was later collectively edited to ensure cohesion of the overall article, with pseudonyms used for anonymity.

A note from the collective advocacy worker

I am very fortunate to be working with the Seen But Not Heard - collective advocacy group for people with experience of eating disorders. Based in Edinburgh, Scotland and part of CAPS Independent Advocacy, the group works together to bring forward the voices and perspectives of those with lived experience of eating disorders. This includes talks and workshops, collective art pieces, conducting experience-led research, and film-making, among other things.

Often there is but a single narrative available for people living with eating disorders. This narrative tells us who can get an eating disorder, what living with one looks like, and what is needed for 'recovery'. The way eating disorders are talked about matters; those who do not fit the dominant narrative, are marginalized and may struggle to receive support. Moreover, it also limits the kind of 'solutions' that are offered.

For this article, the group wanted to specifically focus on the theme of 'recovery' as something they felt was often misrepresented in harmful ways in discussions about eating disorders. The group challenged the linear, progressive notion of recovery as a journey from being ill to being 'recovered'. Rather, 'recovery' is a multifaceted process that might never be fully over. Instead of recovery, the group wanted to highlight the notion of 'living well' with an eating disorder – a journey which involves re-building relationships with oneself and others, as well as with the eating disorder itself.

It is worth asking, what would services and support look like, if they were designed to enable 'living well' – and all the different shades and meanings that this might contain for different people - rather than the often unattainable, homogenising goal of 'recovery'? It is

striking that not a single person in our group reported that professional eating disorder treatment and services had positively contributed to their 'recovery'. While at times services and treatment were simply not available, at other times they were actively harmful.

The system still treats those with lived experience of 'mental illness' or 'madness' as subordinate to the views of 'experts' and medical professionals. By sharing this conversation, the group hopes to challenge this hierarchical notion, using their own words to craft a different way forward. I know that I for one have learned a great deal from them, and I hope others will listen to their voices too.

- *Ellis Kokko, Collective Advocacy Worker, CAPS Independent Advocacy*

What follows is an open dialogue between 5 adults who have all experienced/continue to experience various forms of eating disorders. While there is no explicit mention of numbers, some of the content may be potentially triggering to some.

What does recovery mean to you?

TT: I feel like this is a big one for myself. Since I never went to a hospital or saw a psychiatrist for my issue, I didn't associate the term 'recovery' with myself. At that time, I simply thought, "I don't like this behaviour; it's affecting me negatively, so I need to change it in a way that aligns with how I want to be." It was only after a long time, after I hadn't had symptoms for a while, that I started to reflect on what happened with me in the past, and realized I had some form of an eating disorder. It was only then that I began to think about my 'recovery process'. I believe that if I had been officially diagnosed, my recovery journey would have been different. I can't say what that experience would have been like or how it would have felt like to me. I think it really depends on your particular situation, how you identify and whether you attach yourself to this kind of word or not.

Shanna: I am not sure I can summarise what recovery means to me in a few words. My eating disorder started at 22, and while I also don't feel fully 'recovered' at 26, I am in a much better place now. Looking back, I can see just how much progress I've made. If I want toast, I eat it without hesitation—no more substituting it with sliced sweet potato. It's only in hindsight that I realise how much space those disordered thoughts had in my life. Recovery has been slow and difficult, but the eating disorder voice is now distinctly separate from my own. So recovery has been about standing up to myself against the disordered thoughts; I can hear them and choose not to engage (usually).

Peppa: Yes, there are times when I hear the disordered voice in my head telling me to limit certain things, such as using oil when cooking, but I have rebelled against it, and instead, I put even more oil! With time, I have learned how to manage the disordered thoughts and

not let them impact me, and I suppose that's what recovery means to me— learning how to manage the eating disorder without it affecting your life.

Shanna: Yeah, it's still with me every single day, but it doesn't have the grip on me that it used to. I think what you were saying about the oil is a really important part of it. Feeling that fear and being able to challenge it. Like 'I can't put oil on my dishes…No, I will put oil on my dishes! Like I need to go for a run, but I'm tired. And then not going for that run. It's these little things that scare you. Being able to hear the voice and do the opposite, you feel kind of good after it. At this point, I feel I can have a life with an eating disorder, whereas before, it consumed my life. On my stronger days, I can still hear it telling me not to use oil, and I feel proud of how little impact it has on what I do.

Jane: For me, recovery is a very long, mundane and fickle process. I saw a quote recently about 'recovery being something that you have to do for yourself' and 'that no-one can recover for you', and honestly, it's narratives like that, that just frustrate me. There's always this notion, especially in the West and Western-based models that recovery is the sole responsibility of the individual, and that the individual has the choice and power to make a change. It's really not that simple! It's also frustrating how it is often compared to physical health but it's not the same at all. Anyone can break a leg and there's a fairly universal procedure that works for the majority of people to fix the leg, but that just isn't the same for mental health/illness (and funnily enough, you're not called co-dependent for wanting to rely on a Doctor to fix your leg!)

Nick: On top of my eating disorder, I have a brain injury and I have had 13 brain operations altogether. As a word, 'recovery' is quite problematic, because it suggests getting well. And the big thing for me, and it's not about getting well, it's about living well, as well as you can, without symptoms, that vision of functioning, which is, I wanted to believe years and years that my mental illness was way behind me, so ill, so depressed for so long now. And psychiatrists use the word severe and enduring, and that word 'enduring' is brutal. I never get rid of that shadow. For me, it's a dragon shaped shadow.

Jane: There's so much emphasis on prevention and young people in eating disorder research/treatment which is a good thing of course, but when you walk into services with decades of experience of an ED, you realise what little progress has actually been made. I'm personally doing much outside of services, but that also doesn't mean my ED has vanished, or that I don't face significant barriers to life now (people aren't so understanding of long-term illness). I just started to understand myself better in relation to my eating disorder and together we started to learn to live alongside one another.

Peppa: I feel that there should be more discussion about the different aspects of eating disorders and the reality of recovery rather than promoting it as a quick fix. I believe there should also be better guidance on the other potential outcomes, such as anorexia developing into bulimia or other conditions. I think for me going into therapy, I thought I will

just deal with this and deal with that and have everything sorted so I can just put it in the shelf and everything will be in order. if I need anything I can just open it up and then put it back. And it just doesn't work that way. You will never come to be 'fixed'. You'll just kind of learn to manage and to deal with it, know what to do when things get difficult. I mean you can get better but you don't get fixed, whatever that means.

Nick: That's right. It's not about getting well, it's about living well.

Have there been clear end and starting points in your journey? Do you feel like recovery has been a conscious/unconscious process?

Peppa: It is difficult for me to remember if there was a clear starting point for the ED since it began when I was around 12-13 years old. I don't think there was ever a clear starting point for my eating disorder; I think it was a process of different things building up to this culmination, which was the anorexia. As a little girl, I remember seeing things in magazines or on the TV, for example, how fried food was bad for you, so I started avoiding it. The other thing is that once you start losing weight and receive compliments, it validates this belief.

Shanna: For me, I think it was quite clear, because I was a wee bit older, I'd just turned 22. I'd moved here with the partner I'd had since I was 17. And then we broke up, and I wasn't expecting it. I don't think, for me at the start, it was about food. It was more, like, I felt like the ground was unstable beneath my feet. I needed some form of control, and I started bouldering. For me, it was the narrative of I just want to eat the best things I could possibly eat so I can get better at something I loved… and I guess I just kept telling myself that I was doing it for good because I wanted to get stronger, because I wanted to get fitter, because I wanted to get better… and eventually I had started bouldering every day, and this was over lockdown, so I just didn't have anywhere else to be. By the time I realised that I had a problem, it was a pretty big problem.

Peppa: Yeah, I think for a lot of people it starts with either conscious or unconscious desire to control your environment because in most of the occasions there wasn't much stability in your life. I know I am definitely such a perfectionist!

Shanna: Eventually I was referred to a dietitian, which was completely useless. I mean, dietitians can tell you to eat yoghurt, and I can nod and be like, I'll eat yoghurt and I'll have a smoothie with this meal, knowing I would never do it.

Jane: Did you go through services at all, if you don't mind me asking?

Shanna: Honestly, no. I called quite a lot of times, sometimes I'd phone after I'd left work and I'd be standing in the street and I can't go home, because if I go home I will spiral and no one else is there. I don't have my family in Edinburgh, so I'd be on the phone to the doctor, and then I'd get sent a link to the NHS website. There just wasn't really any help available,

which is kind of scary, I think. For the most part, I had to just figure it out on my own, from people on the internet.

Nick: That's ridiculous!

Jane: I think recovery is a mix of both conscious and unconscious elements. There have been times when I've decided to seek treatment and times when things got better organically. During the pandemic was when I improved the most and that was due to a mix of space and just sheer willpower. I was cut off from people who negatively impacted my ED and I also stopped going on social media. I was basically socially isolated apart from my partner and pets, and it was the best thing for me. I managed to go back to my degree online and actually graduate which felt like a huge achievement. I just slowly started to get my desire to live back.

Peppa: In the beginning, recovery was definitely a conscious effort, not as much anymore. At this point, I'm just living my life. But it was very difficult to go against the ED initially. I just had to remind myself that it's a part of a process and I'm going somewhere, even if I'm not sure where that is. I feel like the progression of illness and recovery is often depicted as straightforward when, in reality, it doesn't always unfold that way.

Shanna: I agree that in the beginning, recovery is incredibly conscious. The eating disorder consumed most of my waking moments, and so the recovery had to also. Eating disorders can take so much away from you; I spent a long time cancelling plans with friends and avoiding family due to the fear of having to eat or drink. It's such a battle at first to fight these thoughts and to not do what the eating disorder tells you; for me, it was exhausting. It's also impossible to rationalise an eating disorder; mine didn't respond to reason or compromise. With time, it becomes easier and more unconscious because the ED voice gets quieter, and you've learned to manage it. Still, in weaker moments or when life is particularly tough, for me, it requires a conscious effort again.

TT: As I said before, I only ever started thinking about recovery long time after I had gone through the worst of it. I believe that now even if things get hard again, I don't think it can ever be the same as it was. Once I have these conscious experiences with food, I can never go back to my previous state. Previously, I might not have thought about why you were doing certain things, like why I should put a certain amount of oil on your food or why you should go for a run. But after these experiences, I start to think about my relationship with food, my body, exercise, and everything else. It won't be the same; it will never be the same.

Peppa: Yeah, it's not like you're going to wake up one day and be the person you were before. At some point, it clicked that my body and my mind were disconnected. I struggled with understanding my body's signals and hunger cues because I had suppressed them for such a long time, and I had to re-learn to listen to my body. It's almost like learning how to walk.

Shanna: Yeah, I agree with what you said! For me, it was about consciously rebuilding my life and re-building my relationships. Just figuring out who I was without the eating disorder, which was a real struggle. Especially since it was tied to obsessive exercise, which I had strongly linked to my identity. It's funny because now, all this time later, I don't know if I enjoyed it because I enjoyed it, or I enjoyed it because I had an eating disorder and it was like obsessive movement. I think it must have been a bit of both.

Peppa: Yes! Finding out what you like or don't like - it took a lot of time. When I realised I was sick, I tried to remember how I was before the ED and what my relationship with food was like before, but I couldn't. I had completely forgotten what foods I like, and it was something I had to rediscover. For example, I've always thought I was a lover of everything sweet, but once I allowed myself to eat everything I wanted, I discovered I don't actually have a sweet tooth. It was just the suppression of eating anything with sugar that had made me crave it even more. It was a whole new process of building a different relationship with food, and with myself, based on what I actually like and don't like.

TT: Yeah, and eventually, you'll understand why you're making these choices and begin to get along with your decisions and your life. It will make you a more conscious person in all these choices, and that's why I don't think it will ever be the same again.

What do you think about mainstream narratives of recovery?

TT: There's one thing I've read before: the idea that women have eating disorders because of their desire to be fit or slim. I think that certainly does not apply to everyone. Many reasons can lead to this problem, and mainstream portrayals often suggest that people choose to have these disorders only to improve their visual appearance or because they have paid too much attention to their appearance, which is ridiculous.

Jane: Yes, I think a lot of the time we're still portraying eating disorders as things that only white women get, who are fixated with their body image and it's just really disappointing that we haven't progressed away from that. I get frustrated by social media where I used to follow eating disorder advocates, but I realised they weren't benefitting me and they were actually just making things worse by reducing EDs to a very specific narrative. I think there's also a lot of co-opting of recovery narratives by psychology and psychiatry whereby only those who went through treatment and recovered get promoted, so you end up only seeing their stories repeated everywhere. It's a really strange culture where we basically have eating disorder influencers now, where it's the same voices dominating the media.

TT: I recently read a book called Crazy Like Us, which discusses the globalization of psychiatric diagnoses. It mentions cultural differences, explaining that diagnostic criteria, like those in the DSM-5, might not apply to other cultures. When using the same criteria worldwide, people may not fit into those criteria and might not recognize they have an eating disorder. This brings back the idea that fitting into these criteria, as established by

mainstream authorities, doesn't necessarily reflect everyone's experience. The reasons, stories, and recovery processes are really different for each person. Unfortunately, we rarely hear diverse perspectives on how different people heal. The predominant narratives, like those on Instagram, suggest a one-size-fits-all approach to recovery. This can lead people still in the recovery process to think, "This is what I should do, this is what I should follow," and if they're not on that path, they might feel they're not on the right track to recover.

Jane: I agree. Recovery in mental health is so subjective that these universal definitions and treatments just don't make sense to everyone. My issue is that eating disorders are still seen as behavioural/cognitive issues and ones of vanity and a fixation on weight/food. So according to CBT, if you fix the behaviours then you're suddenly recovered but it doesn't work that way. I've had my eating disorder since I was a child and it wasn't until my 20's that I was able to even consider a life outside of starvation because I just didn't have a safe environment to do it in. I'd cycled through so many treatments and inpatient stays but nothing worked because I don't exist in an empty space. Sometimes, having my eating disorder was the safer option but you're not allowed to say that.

Peppa: I think it's an unrealistic expectation is that one day, you are going to wake up and be who you used to be before the ED. But that is not what happens most of the time with mental illness. I know every recovery journey is different, but I think it's damaging for people who are at the beginning of their journey to expect that. I know that it is not what anyone wants to hear at the beginning. When we did the carers and parents workshop, one of the mums asked how much time it had taken me to get to the place where I was at that moment in time. And I said, oh, about 10 years. And when I said that, she was really taken aback and shocked.

Nick: I think 10 years is pretty good!

Peppa: I don't follow social media as much now, but I remember when I was younger reading about BMI and saying that after you regain weight, you'll be fine and recovered. After I gained the weight, I couldn't understand what I had done wrong because the disordered thoughts didn't go away; on the contrary, they were getting worse.

Jane: I often got worse in services because there's such an emphasis on food and weight, above and beyond everything else that might be contributing to your ED.I think that's when these words like 'recover' and related narratives can become dangerous: when you don't fit that narrative, and it makes you feel like you're doing something wrong. It leaves little room for any other narrative. For example, during the pandemic the dominant narrative was that people with eating disorders were really struggling, which was true, but not for everyone. I actually thrived during the pandemic!

Peppa: I also thrived during the pandemic! It gave me the chance to challenge the ED. I was afraid of how people would perceive me if I put weight on, and during the pandemic, this

factor was eliminated. I allowed myself to eat as much as I wanted and started to restore some "normal" eating habits, and things balanced themselves out with time. It felt quite freeing and liberating just to have a moment for myself to get used to my new body without that additional pressure and fear of judgment from others.

Jane: I think in my case it offered me the physical and mental space that I needed to better understand myself in relation to my ED, and it got me out of the services that I realised were incredibly harmful to me. By creating this one narrative that everyone was suffering, it marginalises those who don't fit in and creates this homogenous understanding of an eating disorder.

What does living well with an eating disorder mean? What has helped you?

Peppa: I used to spend a lot of time worrying about food—what to eat and especially what not to eat. It consumed a big part of my life. Living well to me means being able to go out with friends for a meal or a drink, or letting someone else cook for you, or just eating whatever, whenever. It's about balance, feeling good about yourself and your body instead of hating and being in tune with your body. I am not a master of everything; there are good and bad days. It is never back and white. Balance! There isn't much space for balance when it comes to EDs.

TT: For me, it is about being happy with what I eat and how my body feels. Feeling comfortable is important, like ensuring my stomach feels good. It's also about allowing myself not to exercise if I don't want to and having empathy for myself. My past experiences made me harsh on myself, and during my university applications, I started to feel out of control and anxious. That's when my eating disorder began. Being able to connect my body with my emotions and cope with my anxiety - this is what recovery means to me.

Peppa: And as I mentioned, I had created this story in my head that you have to be skinny for people to like and love you. What helped me most, among the other things I talked about above, was my partner showing me that people can love you regardless of how thin you are. I learned that my value is not in my appearance but beyond that. This realisation was incredibly influential in my recovery. Now, I'm working on having a healthy relationship with exercise. I believe that as we age, exercise is vital for overall health, but I had to give up any type of exercise because I was focused on how many calories, I could burn rather than on building strength or endurance.

Shanna: For me, what has been important is talking about my experiences without shame when things get tough, this has been incredibly helpful. When I eventually opened up to my mum, who is a recovered alcoholic, the similarities in our experiences were striking. Having someone you love understand what you're going through and be living proof that you can heal and have a good life makes living with it all the easier.

TT: Yes, the support of the people around me was crucial, and I remember it vividly because it was so influential during my recovery process. They didn't treat me differently or act like I had a problem. They treated me the same as always, which made me feel 'normal' and not strange or special. Because of this, I didn't feel the need to pay extra attention to what I ate, my body image, or how I interacted with them. When I gained a lot of weight after going "all in," I was worried about how my teachers and friends at school would react. But none of them mentioned my weight change, which made me feel very lucky. When I was younger, I cared a lot about what others thought of me, so their lack of reaction created a safe space for me to change in a way that felt right to me.

Jane: I think what was helpful in my case, was taking the time to really unpack my eating disorder; I did this myself and then later with a private therapist who I'm lucky enough to see. Just being able to leave diagnostic labels and treatments that advocate for total abstinence of ED thoughts/behaviours at the door has been really helpful. It's given me the chance to basically have a conversation with my ED and get to understand it. I've had my disorder since I was a child and because of that I've developed a pretty strong bond with it. I know what it looks like, how it feels, how it sounds, and it's quite literally saved me during various points of my life. So, if some psychologist comes along and gives it a name and tells me to get rid of it because it's only dangerous and unhelpful, it's kind of a red flag. It tells me that they aren't willing to listen to me as a person with my own experience.

Shanna: Yeah, I think in time you learn, even if it doesn't go away, you learn to be kinder to yourself about it. For me a big part of living well was understanding this; learning to be more compassionate with myself about my eating disorder. EDs are scary and overwhelming and made me feel completely out of control. It becomes nearly impossible to imagine your life without it. For me, I had to understand that these thoughts and behaviours emerged at a time when I needed to feel in control of something while my life was otherwise completely unstable. Although the eating disorder was obviously harmful, I recognise that it became part of my life as a misguided attempt to help me cope.

Jane: Yeah, I think similarly to be honest. My current therapist is the first person that's actually accepted, and acknowledged my eating disorder voice. And she works with me to harness a more compassionate relationship with myself and my eating disorder.

Shanna: I guess when you accept it, it feels less like an enemy as well. Which makes it a lot easier. I now try to see the eating disorder as a part of me that was forced into an extreme role. The gentler and more understanding I am with this part, the easier it becomes to deal with the thoughts it provokes. Self-compassion has been key in my recovery. Instead of punishing myself or deeming myself incapable of recovery, I acknowledge this part of me, I even thank it for what it is trying to help with, but then I ask it to consider easing up and trusting me to handle the situation on my own for now. Changing the narrative from having this scary thing inside of me that inhibits my quality of life to just having a part of me that is trying to help in an unhelpful way makes it a great deal easier to live well while in recovery.

Jane: Yeah, just to have the opportunity to be able to step back during difficult times and say ok ED, I understand why you're here right now and I appreciate your concern, but let's try something different. Being able to do that is so powerful and so much more helpful than anything I've experienced in any eating disorder service. This kind of exploratory work is allowing me to create a more compassionate self and really own my narrative. It's empowering, and I think that's my understanding of living well with my ED.