Lived experience of an eating disorder

Katharine Lazenby†

A common misconception of anorexia is that it is a faddy, vanity-driven diet that has gone too far; a willful lifestyle choice that simply requires a decision to "just eat" in order to recover. I would have saved myself years of agony and time lost in inpatient care if it were really that simple.

Between the ages of 19 and 32 I had more inpatient admissions in specialist eating disorders units than I am able to count (some of which lasted as long as a year or 18 months). One of my consultant psychiatrists calculated that in my 20s I spent more time locked in a hospital ward than I did living in my own home. Having slipped into the merciless grips of an eating disorder, I found it impossible to prise myself free. For many years it felt like trying to escape quicksand – the more I struggled to find solid ground, the deeper I sank.

If you get to know and understand eating disorders, you'll come to realise that they serve a powerful function for the individual; some of us may go so far as to say the illnesses are in many ways beneficial, rewarding even. They are often a response to a deep and profound unmet need or buried conflict. Providing a sense of control, escape or comfort, they often arise in an attempt to cope with things that feel overwhelming, chaotic or frightening. They are the answer to an unresolved question, the solution to a knotty problem.

I felt both suffocated and comforted by the python-like grip of my anorexia. I had many moments of clarity where I could see it was destroying me, jeopardising everything in my life, and yet I still wanted to be held in its embrace.

It was dangerous, but felt safe. So, for years it kept pulling me down. The paradox is that to others my eating disorder looked like I was giving up on life, a slow suicide, but I believe that on some level it was my way of trying to save myself.

Retreating into my eating disorder numbed my emotions and fogged my mind: anorexia was the perversely literal solution to having "a lot on my plate", thoughts that are too much to bear and emotions that are impossible to swallow. My eating disorder steadily disconnected me from reality, turning down the volume on a deafening world and providing an escape from unwanted responsibilities and feelings of powerlessness and insecurity. It gave me a language to communicate how I felt about myself, a channel through which to process how overwhelming I found life. Since I was a young child I had struggled with a painful feeling that that I didn't fit in and would never belong. I felt inadequate, like I was constantly failing, consumed by a belief that there was a right way and wrong way to behave and that, somehow, I was never getting it right. Wracked with obsessive anxiety, as I reached my late teens, managing life felt increasingly puzzling and difficult to grasp and my feeling of being a misfit had turned into extreme self-loathing. This was compounded by unprocessed anger and trauma from homelife challenges I'd faced growing up, which I turned inwards, fueling a toxic belief that self-destruction was the only answer. Whilst I did not consciously choose to develop an eating disorder, it makes sense that an eating disorder chose me – the roots of the disorder were growing thick and strong long before my anorexia surfaced. Life, and being me, felt intolerable; the eating disorder offered an enticing escape.

Hyperfixating on calorie control or weight loss provided a powerful distraction, and something I could have command and control over – a way of turning away from the seemingly unsolvable problems that really ate away at me: "Who am I? What do I want? Why do I feel like I never fit in? How do I cope with existing?" or managing the feelings that threatened to drown me: self-loathing, guilt, anger, fear, anxiety. For a long time, I chased self-worth through the destructive behaviours of my eating disorder, and I built an identity around it.

But I do not want to romanticise the illness or sugarcoat its actual cost and impact. I nearly died, a number of times, because of it. My first breakdown forced me to drop out of university and whilst friends were graduating, moving house, building careers and settling down, I was circling in and out of hospital, my physical and mental health unravelling over and over again. I lost friendships along the way and family members were devastated, witnessing my seeming inability to remain stable and the increasingly intensive forms of treatment being introduced to try and save me. I was sectioned multiple times, was too unwell to work during my 20s and deemed too unstable to live independently, so for many years I lived in supported housing. Inpatient care saved my life, but the admissions were also soul-destroying and traumatising. Disconnected from the outside world for extremely long periods of time, I found it hard to see myself as anything more than a patient or diagnosis, or to believe in the possibility of a future beyond the hospital walls.

I often became more unwell upon admission, with an intensification of my anorexic behaviours and other issues such as self-harm. The reasons for this are complex but the hospital environment had a major part to play. In the intensely distressing, frightening and restrictive world of the ward, the comfort of my strict anorexia rules and behaviours felt to me more essential and "lifesaving" than ever, the only way to hold on to a sense of autonomy and control. I knew there was no way out without complying with treatment and yet letting go of my eating disorder felt impossible. The upshot would be, however, extreme forms of treatment used by my care teams to keep me alive (sectioning, physical restraint, antipsychotic medication, nasogastric feeding). Sometimes the grip of care felt like it echoed the grip of my illness.

The "escape" my eating disorder offered in reality kept me in a prison; life moved on without me. In lots of ways my anorexia has been an illness of paradox and tangled contradictions, trapping me in a labyrinth of back-to-front thinking. At times, not consuming food has been an all-consuming preoccupation. In the doctrine of anorexia, "need" is redefined as "greed", appetite becomes denied, displaced and demonised. Anorexia made me desperate to disappear and yet terrified of being abandoned or ignored. I felt the drive to both achieve, stand out, be exceptional but also to self-destruct.

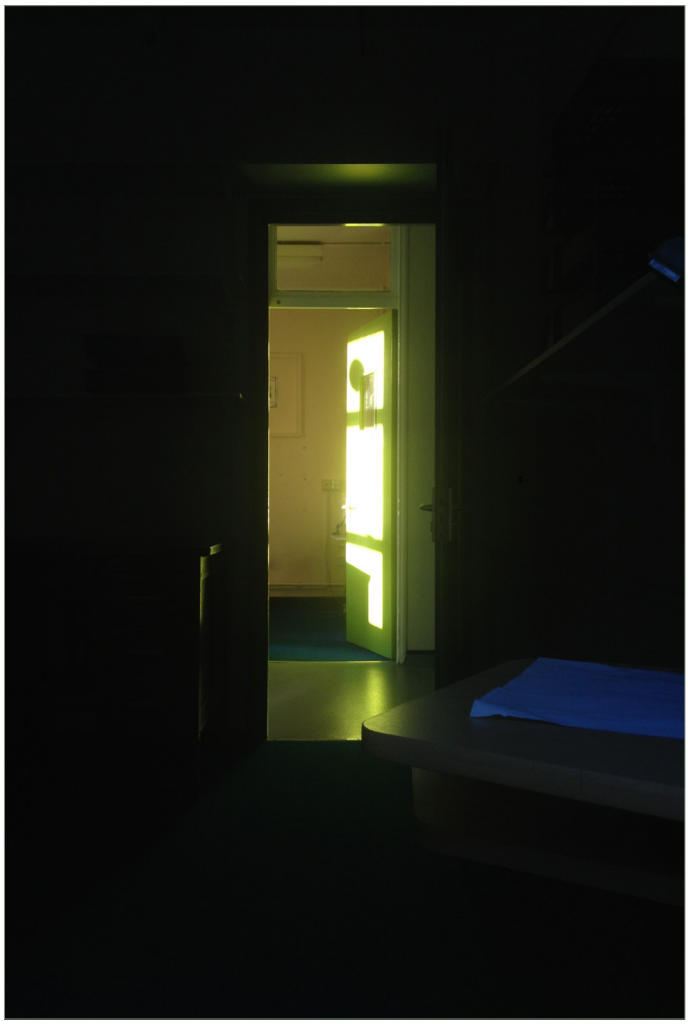
Anorexia laid down strict rules for me to obey, punitive standards to attain, but also kept moving the goalposts; nothing – quite literally – was ever good enough. These rules brought me comfort, but they also tied me in agonising knots and attempting to bend or break them triggered overwhelming anxiety and panic. The fears my anorexia induced were irrational, but they were also crippling and deeply rooted, impossible to battle with reasoning or logic alone. Family and healthcare professionals often tried to rationalise with my thoughts and behaviours, the apparent symptoms of my eating disorder, by telling me why I should eat more and offering practical advice on how. But I knew the reasons why recovery made sense. I knew that the things I wanted – to complete a degree, have a job, a relationship, a home – were incompatible with the unwavering commitment to denying myself nourishment and keeping myself teetering on the edge of starvation. I was not lacking in knowledge about the needs of my body, and I understood the concept of self-compassion and self-care. Reason was not enough because it responded to the eating disorder at the level of symptom rather than cause, like cutting down a tree and leaving its roots intact.

When I tried to resist the demands of my illness, anorexia would tell me I was losing control. Family would plead with me to "fight", but, in the grip of anorexia, fighting felt like losing and "winning" against the disorder felt like failing. I wanted freedom beyond the constraints of illness and hospitalisation. I wanted to stop wounding my family, and to stop being weighed down with the shame I felt at being stuck in a stagnating life. But "complying" with treatment plans and turning my back on my eating disorder threatened the loss of my most potent coping mechanisms. So, for years, I was filled with ambivalence about recovery and could not see a way out.

"And the day came, when the risk it took to remain tight in a bud was greater than the risk it took to blossom" - Anaïs Nin

I carried that quote around with me, in and out of hospital, for years before I started to embody its truth. Just as each person's eating disorder is unique to them, so too is each recovery. I made promises – to myself and to others – that I would get better, that I would not end up in hospital again, over and over. Shame and grief wore me down with each broken promise and as years went by, hope slipped through my fingers. I didn't make a conscious decision to walk away, rather than towards, anorexia. I didn't consciously commit myself to weight restoration or put into practice a concerted plan to steadfastly rid myself of self-destructive urges. Yet somehow, in the last six years, the balance of my health and behaviour has started to tip more towards recovery than illness. I started, almost without fully realising it was happening, to say "yes" to life.

My last hospital admission was in 2017. That year I was diagnosed with cancer. The psychological and physical devastation of this triggered another major eating disorder relapse and I ended up, once again, sectioned in an eating disorders unit. I was transported daily by ambulance to a hospital on the other side of London to receive chemo and radiotherapy. I frankly can't find the words to describe how bleak that time was, how utterly broken and hopeless I felt. That year I came face to face with the precarious fragility of life, with the brevity of the time we have, in a way I hadn't felt before. I came out of the experience with a feeling that perhaps I didn't want to keep depriving myself, that I was tired of being disconnected from my own life and fed up surviving in the smallest confines. I think that there has always been a spark within me that wanted to live, but for a long time I kept it small, barely perceptible at times; perhaps I was afraid of it, or protecting it too carefully.



Anorexia has been that protection, but in recent years I have come to resist its deadly constriction and take back the life it threatened to suffocate. I actively want to live rather than just survive. This has meant saying yes to pleasure, to appetite, to fun, to taking risks and having adventures, to finding my voice, my power, my strength and feeling my emotions in their full and terrifying force. I have a successful career, a marriage, qualifications, a home, passions, hobbies and friends. I have been places and done things I never thought I would ever be capable of achieving. My life, compared with a decade ago, is so dramatically different that sometimes I cannot fathom the trajectory.

I would be lying if I said I was recovered. The truth is I would still describe myself as someone who lives with disordered eating and who is working on understanding and loosening the knots of my behaviour. But I have freed myself enough to be able to grow and heal, and this gives me hope and optimism for the future.

I am often asked how I have changed direction, what has enabled me to move forwards. Inpatient care caught me in crisis and kept me alive, and the wide variety of therapy I received has been instrumental in helping me to understand myself and process things I couldn't face alone. But there were times being in treatment compounded my issues and kept me disempowered and lost to myself. I had to find ways of meeting my needs for connection, fulfilment, control and autonomy that weren't tied to illness or clinical care. So, for me, recovery has also been nurtured by creativity, relationships, travel, by the discovery of hidden talents and passions, finding work I enjoy and opportunities to own the story of my experiences free from shame.

I have spent the entirety of my adult life attempting to understand myself, trying in particular to get to the heart of why I became so unwell and why life, even today, often feels like an immense and perplexing struggle. I have spent hours unpicking my thoughts, feelings and behaviours with therapists, doctors, nurses and anyone else I felt safe enough to open up to. I have talked and talked, rationalised and made connections, "processed" and linked event A to reaction B, over and over again. It has been undeniably useful in many ways but also demoralising; despite all the talking, my challenges – particularly my crippling anxiety, low self-esteem and anorexic tendencies – stubbornly persisted. In all that time though something crucial was overlooked.

Then a few months ago I was diagnosed as autistic, and a key missing link fell into place. Research conducted by the

PEACE pathway, specifically developed for the treatment of eating disorders and autism, has found that around 35% of people struggling with eating disorders are autistic or display autistic traits. I worked extremely hard to camouflage most of the difficulties associated with my neurodivergence, so it is not surprising that it took so long for me to be diagnosed. But without a doubt autism has played a key part in my eating disorder, underpinning many factors that led to its development in the first place and exacerbating the immense challenges I have faced in trying to recover. It is painful to realise now how much misunderstanding I have encountered – staff and patients who criticised and judged my meltdowns as attention-seeking and histrionic, the misdiagnosis of my autism as borderline personality disorder, or failures to appreciate how devastatingly destabilising I found change or transition.

Reflecting back on my life now, applying autism as a context, I cannot help but wonder whether the years I spent in the care of mental health services might have unfolded very differently had people understood this fundamental aspect of who I am.

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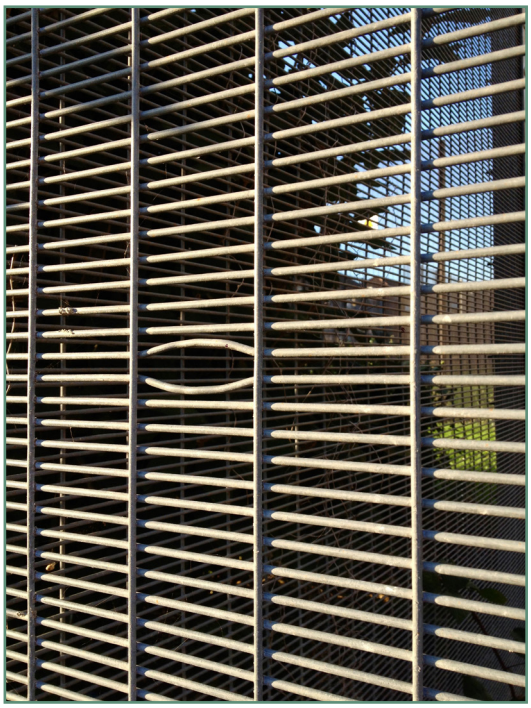
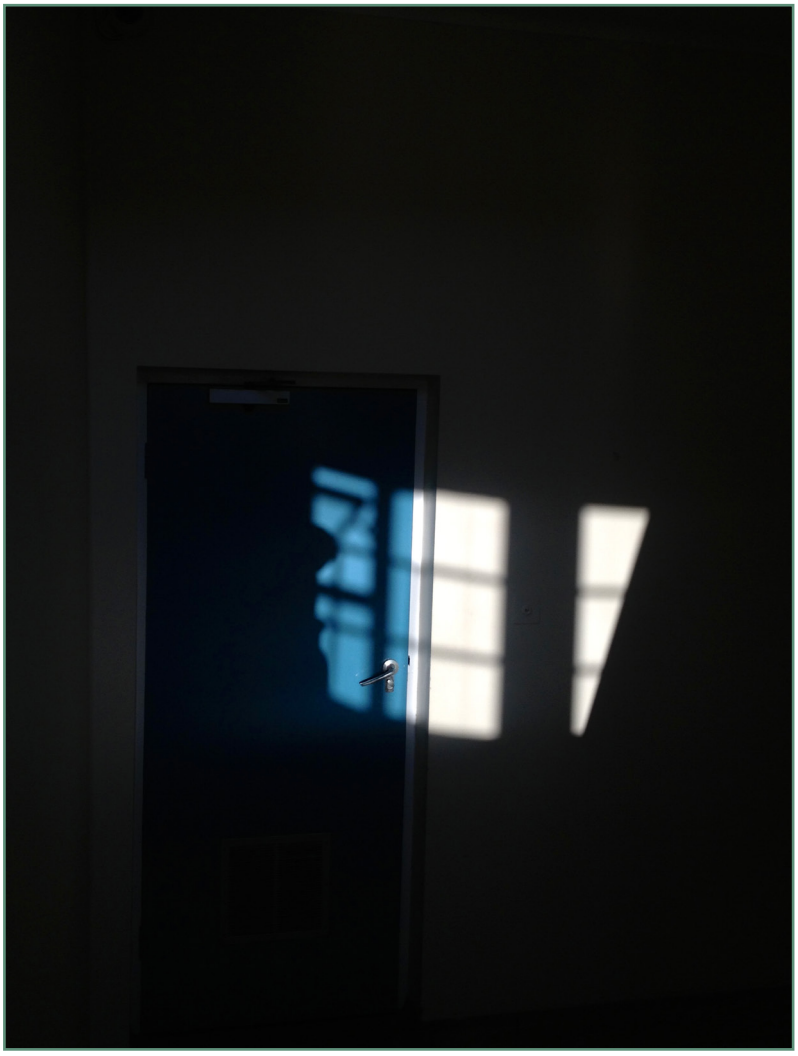
Katharine is also a visiting scholar at London Southbank University, where she lectures on psychologically informed environments and eating disorders, and has spoken at a number of national conferences about her lived experience of mental health care and recovery.

She sits on the board of directors for the Design in Mental Health Network (https://dimhn.org) and is a trustee for the art and mental health charity, Hospital Rooms (https://hospital-rooms.com).

Katharine is also a practicing artist, exhibiting when she can find the time! She is passionate about the importance of centring lived experience in mental health training and education and the power of creativity in nurturing growth and recovery.

The photographs accompanying this article were taken by Katharine while she was an inpatient receiving treatment for anorexia nervosa. More of Katharine's photography is featured on the Cutting Edge Psychiatry in Practice website.





All photography by Katharine Lazenby.