
Lived Experience

Extracts

CONTRIBUTING FACTOR

"...At 18, I suddenly didn't feel right about the impending adult changes in my life. Soon I'd be leaving home and going to university... I felt like things were moving and growing, and I wasn't sure I was ready to grow with them ...

There was a vulnerability within me which meant that I was less able to deal with taking ownership of the changes within me than other people going through the same experience..."

- Grace

COMMUNICATION AND PERCEPTIONS

*"...Dinner ladies told me how well I looked today. How?? – this means if I put on weight, I'll be fat.
I am already big
That's what people see and mean
I am bigger than I want or should be
Help me
Help
Help
I'm crying at my failure ...at my confusion
I'm scared ...worrieda failure..."*

- Emma (2007)

"Mum kept saying about my weight this morning- a lot! I wish people would talk to me about things other than food/weight statements or questions. It always makes me feel so trapped...."

- Emma (2004)

"...Everyone thinks I'm ok again because of my weight gain from before, but my mind still plays tricks on me and dictates... I'm stuck !!! ☹..."

- Emma (2004)

PSYCHOPATHOLOGY

Function – Choice – Suffering vs Fulfilment

“...Beneath layers of the achieving Grace, there was a lack of self-confidence... food restriction was the mechanism that initially helped me feel less fragile...”

- Grace

“About ‘Ana’... Ana seems cruel – but also kind. For she allows perfection, control – mia is that awful one who finds the bad self in me and lets her out once in a while – but she tries to purge that out- but she tries to purge that out-

Ana gives you control – perfection – thinness – success – but deep down, I feel sadness, emptiness, loneliness, trapped, helpless. I feel inclined to follow ana but I also feel I want to be free – free from her- she's trapping me – and I don't want to be imprisoned anymore for I know there is more to life – being happy, joyful, good company, fun...

...Ana is a temporary way of satisfaction – but the cruel voice when the scales don't go down – ‘you're NO GOOD, you're FAILING, you're FAT, you're UGLY, you're HopeLESS.’

...my tummy just rumbled – it's empty.... I need something to eat, but if i do, I'll fail ana that day...

The thoughts in my head right now are... ‘will I eat tonight’ – I am saying Yes AND No...

Even if I say yes, itll end up a no anyway, cos when the food is in front of me, ana takes over, she consumes me saying, ‘no no NO DON'T!!!!’ and it's this that stops me every time...

I always say ‘tomorrow’ I'll take my step to recovery, but as the saying goes, ‘tomorrow never comes’ ... I'm weak and pathetic. Ana lets me know that, for neither do I please her, nor do I succeed in a final decision to ‘recover’.

Ana is her name. She is my friend. Also, my enemy. Gives me success....But tortures me. She teaches me... who I am...pathetic, self-control, etc.... but also denies me of who I am. She controls my mind... never sleeps... maybe that is my issue in struggling to sleep.... Her voice echoes through my blank mind, consumed so much to the very point, that its all in my mind, it and.... only it!”

- Emma (2007)

“...Please understand that I don't want to do that [self-induce purge]. My stomach cramps, my eyes become bloodshot, and I feel like I am going to die. Sometimes I bleed and I don't even care. No one would do that in order to control their weight...”

- Leigh-Ann

“...I keep getting the same nightmares of stuffing the self with food and waking up fat. last night I dreamed I looked in the mirror at my throat and I could see right down my throat and a view of my heart, and the voice box because the vomiting had worn away the throat. Then I dreamed again id eaten far too much. Stuff my face. I don't know how to make them stop...”

- Emma (2005)

"...what ambition can this fill... I see nothing.

It's my belonging. Control. Net of safety.

My way of proving how much I don't need care...love, rather be without notice for im ashamed

No matter how small I get – the selfish, unworthy me cannot seem to disappear... the more i lose, the more satisfaction I feel, the more selfish I am. For I have achieved something ive aimed for.

But it's never enough..."

- Emma (2007)

"I often went entire days without speaking – unable to get a word in over my inner taskmaster who never shut up....

You fat, disgusting slob, you'll never be thin enough, good enough, smart enough, tough or talented enough"

- Aimee

THE LONG BATTLE

"I get up in the morning. The constant stressing of weight and looking fat.

Struggling, struggling. Nobody really understands the urges, cravings, and bingeing. It's a lonely road.

My eating disorder has been a friend to me for over this past twenty years, but I am fed up with the constant thoughts going round in my head, and the self-harm and suicide thoughts.

Today I hope is a better day. Oh, how am I going to get over this fight going on in my head – eating, not wanting to eat, fasting, craving and the urge to be sick and to binge.

Every day is always the same - constant feelings of guilt if I binge, and then I purge. Twenty years is a long time. I'm not helping myself.

I am failing all the time."

- Eileen

THE EATING DISORDER VOICE

"...I got my first therapy appointment in the post today. It's for Monday 14th May... soon.... I feel so anxious, scared, and confused. I don't want to be gone from it [eating disorder] in one way but in the other way I do... it's like there are 2 voices... . i am me. Then there is someone else.

Person 1 *'I want to be thin. I want to lose more. I don't want to get over 'this', It's been with me for so long. It just scares me. People will see me as greedy and fat, not want to accept me. I am so embarrassed and feel not me if I put on weight. Help 😞 I don't want to go to therapy.'*

Person 2 *'I want to eat and enjoy food, and eat what I cook, not do any of the 'habits'. I want to be free. I know if I eat, I can socialise better'*

Person 1 *'I don't want to gain weight'*

Person 2 *'I know deep deep down I will probably look better, and I should but I hesitate with the thought of weight gain'*

I don't want to put on so much weight.... I don't want to be a big person, im not important or loveable. Being in a big body doesn't make sense. A contrast and lie of who I am...

I am small....small...small...small....i want to stay small.....

Sometimes my feelings are just nil. Empty...Just like my tummy should be.

I am incompetent. I am not successful at anything, even ana. Im not like others though, I never do it quite as good 😞

I just want to be good enough, be acceptable, normal and fit in – better than what I am

- weight loss helps me control. I find it hard, I am stupid, yes, but for now it's goodnight, it's good to get this out..."

- Emma (2007)

ON RECOVERING

"...Unfortunately, things actually get worse before getting better... we have to be willing to look our worst nightmare in the face... Our therapists, dieticians, and doctors will tell us we are doing great. Despite the fact that we are doing well, we are feeling bad. This is progress, and it means things are actually getting better" ... slowly the horrible feeling begins to actually feel good..."

- Jenni

"...I can see all the positives of 'recovering' but the fear takes over... Ana consumes that, eats up all the things that might positively influence me to 'recover; ... she attacks me... I always see thin people, thinner people.... And that's especially when I see myself as fat, unsuccessful...a hypocrite..."

- Emma (2007)

REFLECTIONS ON RECOVERY

“...the suffering didn’t begin the day of the eating disorder -it began before . Life would never be the same after certain traumatic events for that child – Empty, lost, lonely, and sad, in an attempt to help herself... and to survive, that little child reached out in the only way she knew. Unknown to her, she was soon to lose more... subtly an eating disorder lodged its way into her life and that child soon found herself trapped in a vicious cycle of starvation, exercise, vomiting and bingeing.

At 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, life should have been fairgrounds, ice-cream, concerts, fashion, friendships, music, and family – yet it was not so – it was all consumed by darkness, self-hatred, destruction, and isolation.

That little child was me, and as I reflect, I realise words can never sufficiently capture the unending pain and emptiness experienced in life with an eating disorder –

*And whilst nothing can bring back those years, I would like to fast-forward - Today my heart is grateful for hope - **grateful for the discovery that light exists despite the darkness. Darkness doesn’t have to be the end part of the story.***

*Recovery for me means I get the chance to enjoy life – to have discovered self-worth is found not within the external being but within the confines of the heart. It’s the **freedom** to be able to make decisions not driven by fear and no longer be controlled by the eating disorders voice. It’s pretty special when you have lived so long without that you know.*

*My heart is grateful to **family, friends and professionals** who stuck by me in dark times, sometimes holding my hand, sometimes gently probing me forward and catching me when I fell back. If I can only now share with others the kindness and compassion that was so graciously shared with me.*

Thank you to each and every one of you who seek to help people just like me – just like that little fearful child – thank you for holding onto hope – some days it might feel like its running out, but hold on, recovery is possible, and with every new day comes new strength.

Don’t worry about getting it all right – it won’t happen that way and that’s okay – as the quote reminds us, ‘people may not always remember what you said or did, but they will always remember how you made them feel’. Recovery is a long, hard road, but a precious and valued place to be...”

Dedicated to Philippa

- Emma (2023)

References

- Aiken, J. (2007). *Emma’s Diary*.
- Aiken, J. (2005). *Emma’s Diary*.
- Aiken, J. (2004). *Emma’s Diary*.
- Bowman, G. (2006). *Why I became Anorexic*.
- Leigh-Ann. (2000). *To Those Who Don’t Understand*.
- Liu, A. (2008). *Gaining: The Truth About Life After Eating Disorders*. Grand Central Publishing.
- NHSCT. (2018) *A Road of Greater Things*.
- Schaefer, J. (2007). *It Gets Better: Not just for everyone else*.