University of BRISTOL

Avon and Wiltshire NHS
Mental Health Partnership NHS Trust

Between a Rock and a Hard Place

Students with Eating Disorders

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Handout to accompany a presentation to the Student Health Association Annual Conference, 2014

Aims & Outcomes

Aims

- Provide a brief introduction to eating disorders: what is an eating disorder and for whom?
- Give voice to the dilemma facing students and the challenge for us as health professionals
- Explore professional responses: *Whatever* your role

Learning Outcomes, by the end of the session you will

- Know of the revised DSM classifications of eating disorders *and* have sampled the lived experience
- Appreciate the risks of EDs and the associated healthcare requirements
- Recognise the challenges faced by students
- Have had the opportunity to consider how *you* might better enable students who are living with eating disorders

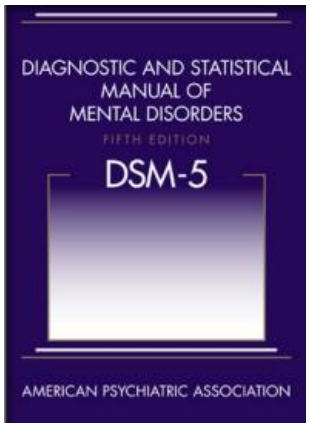
Acknowledgements

I owe a debt of gratitude to the clients who have taught me so much, to Katie Green who has given her time and her art so generously, to Anne who has some advice for health professionals, to my colleagues at the University of Bristol Students' Health Service who have worked so hard to ensure the needs of students with eating disorders are being addressed, and to all the colleagues who have helped me with this presentation.

Illustrations with kind permission of Katie Green taken from *Lighter than my Shadow* (Random House)

I: Introduction

What is an eating disorder



…and for whom?

What are eating disorders?

Eating and feeding disorders are charaterized by persistent disturbance of eating or eating-related behaviour that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning (APA, 2013)

An incredibly complicated mental illness brought on by deep set psychological issues. It can be very variable from case to case but when a disorderly pattern of eating begins to consume and control your everyday life, I believe you have an eating disorder.

DSM-5: Feeding & Eating Disorders: *Symptom Clusters*

- Pica
- Rumination Disorder
- Avoidant/Restrictive Food Intake Disorder
- Anorexia Nervosa
- Bulimia Nervosa
- Binge Eating Disorder
- Other Specified Feeding or Eating Disorder
- Unspecified Feeding or Eating Disorder

Anorexia Nervosa

- Dietary restriction leading to underweight
- Fear of weight gain OR behavior that interferes with weight gain
- Disturbance in experience of weight/shape experience, undue influence of same on self-evaluation, lack of recognition of seriousness of underweight

Eating differently to everybody else… Since April 2008, I haven't had one cooked meal. …I have lost control of my weight and this upsets me. …I feel happy that I can see my ribs and I hate my chest when it becomes flabby like breasts

Bulimia Nervosa

- Recurrent binge eating
- Recurrent compensatory behavior to prevent weight gain
- Undue influence of shape/weight on self-evaluation

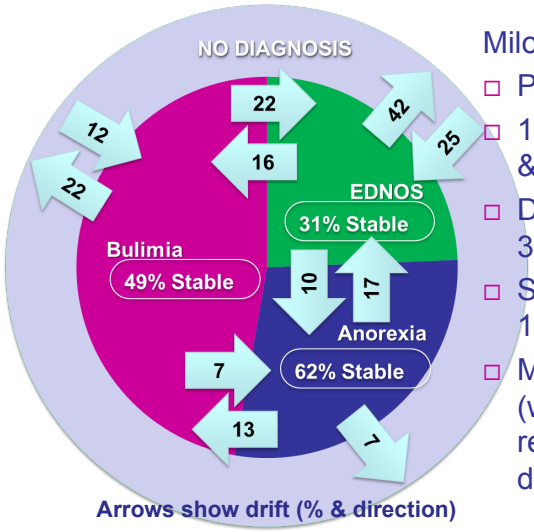
It is my daily life… so it's perfectly normal. …I wish I didn't have this because it costs so much money, but it keeps me slim, so unless I can find a way to eat anything I want, and stay slim as I am now, this seems the best solution.

Binge Eating Disorder

- Recurrent binge eating
- Eating rapidly, until feeling uncomfortable, large amounts when not hungry, eating alone because of embarrassment, feeling disgusted, depressed, or guilty
- Marked associated distress

I really hate myself. I manifest this hatred with my eating - when I'm sad, I eat. When I'm lonely, I eat. When I'm bored, I eat. When I'm feeling bad about myself (most of the time!), I eat.

The Diagnoses are NOT Stable



Milos et al., 2005

- Prospective study
- 192 women at 0, 12 & 30 months
- Diagnostic stability 30%
- Stable remission 13% (?recovery?)
- More than 50% (without stable remission) showed diagnostic flux

"To me, an eating disorder is not ultimately about food, weight, body image, etc., although this is how the illness presents itself, it's a mask for what I call 'the real issues'. …a real need to try and take control of my life… very low self-worth and self-esteem… self-punishment; a way to run away from facing enormous fears, such as "life" and growing up – being an adult..."

II: Voicing the Dilemma

Between a rock and a hard place:

- The challenge for students living with eating disorders
- The challenge for health professionals working with them

…a Rock and a Hard Place

"I hate having 'unhealthy' food as it makes me feel bad but my taste-buds love it! I hate having a fat body and like to be toned and slim, but I like wearing healthy sized clothes. It's a constant conflict - one side of me against the other!!!

For me personally I have found when suffering with an eating disorder - it doesn't matter how thin and how low your weight may be - you are still never thin enough or good enough. You still haven't achieved enough."

"I feel completely trapped by something that started in childhood as a way of coping with abuse. I feel I have carried on this abuse in the way I treat my body. I feel better about myself when I am able to control / restrict eating but this is very difficult to maintain. I struggle with negative feelings about my self on a daily basis and that food issues dominate my thinking most of the time. I feel overwhelmed by the difficulty…"

"I feel completely trapped by something that started in childhood as a way of coping with abuse. I feel I have carried on this abuse in the way I treat my body. I feel better about myself when I am able to control / restrict eating but this is very difficult to maintain. I struggle with negative feelings about my self on a daily basis and that food issues dominate my thinking most of the time. I feel overwhelmed by the difficulty…"

Eating Disorders are SERIOUS

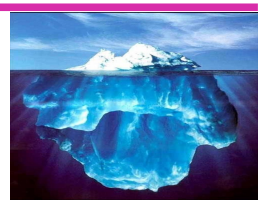
"…I was admitted after falling unconscious and when I came around the drs told me I was lucky to still be alive and if they didn't get iv's into me asap I would surely die. Fortunately I didn't but it was a terrifying experience, yet still I was discharged with no care plan in place." (Beat, 2013)

Eating Disorders are SERIOUS

Eating disorders have some of the highest morbidity & mortality rates of all mental health problems (Striegel-Moore & Bulik, 2007)

- Five-fold increase in mortality associated with an AN or BN diagnosis
- Risk of suicide raised by a factor of 33
  Harris & Barrowclough, 1998

Facts & Figures



- 1.6 million people in UK affected ≈ 10♀ : 1♂
- 5% lifetime prevalence all EDs; 6.4% of adults
- Anorexia Nervosa 0.7% (♀) and 0.1% (♂)
- Bulimia Nervosa 1% (♀) and 0.1% (♂) & EDNOS 2.4%
  Fairburn & Harrison, 2003; NCC, 2004
- One year prevalence in young ♀: AN 0.3%, BN 1%, BED ≈1%
- Majority unknown to services, small minority receiving mental health care
  Hoek & van Hoeken, 2003

Facts and Figures II

- Detection in 1ry care (Micali *et al.,* 2013):
  - All EDs = 37/100,000: Increase 2000 – 2009
  - ↑prevalence or ↑detection? …quite possibly both
- 20-29 y.o's — Per 100,000 in 2009 — Per 10,000 (General Practice)

AN =	♀ 18.9 ♂ 1.8	≈ 2
BN =	♀ 31.8 ♂ 4.7	≈ 4
ENOS =	♀ 37.8 ♂ 3.2	≈ 4
SUM =	♀ 88.5 ♂ 9.7	≈ 10

*Underlying incidence likely to be 2-3x higher

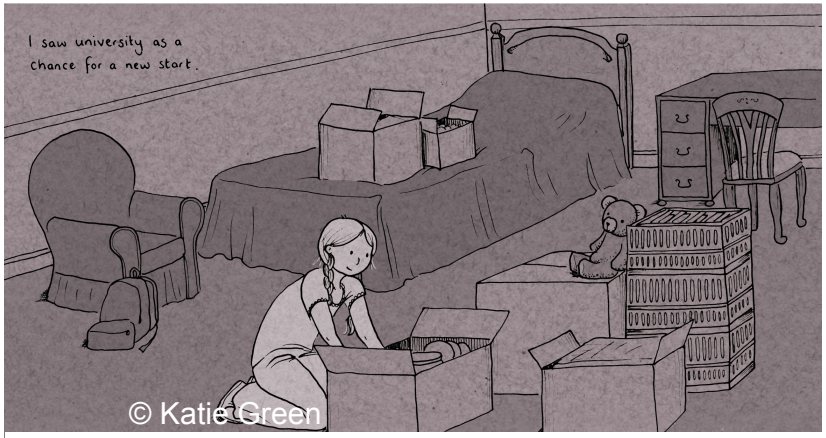
- Peak onset (Micali *et al.,* 2013)
  - ♀ =15-19 years
  - ♂ = 10-14 (ednos), 15-19 (an), 20-29 (bn)

Challenges for Students

What eating disorder were you diagnosed with at Uni? (N=219)	Frequency
Anorexia Nervosa	168
Bulimia Nervosa	70
Binge Eating Disorder	13
EDNOS	51
Total	302

When were you first diagnosed?	N	%
Prior to university & unwell on starting	115	53 %
Prior to starting university but recovered	35	16 %
Whilst at university	69	32 %

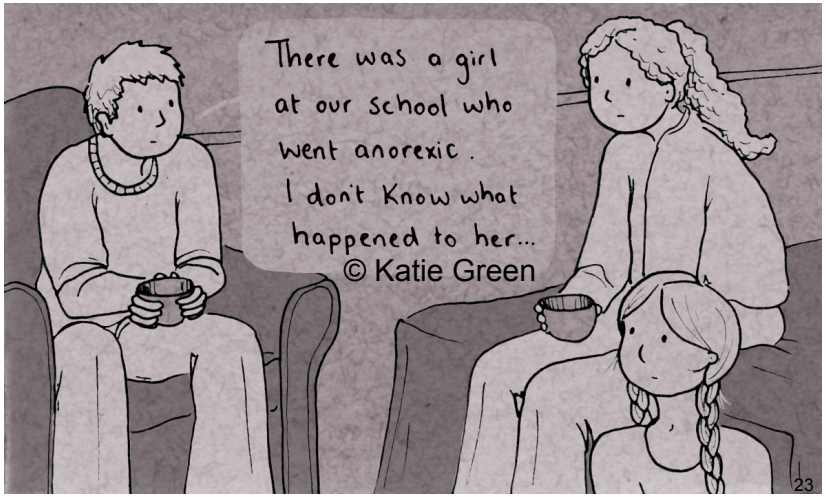
Beat, 2013



"When I started Uni it was my intention to try and beat my eating disorder, I thought the change of area, and different circumstances would aid my recovery but unfortunately the support I received – actually the lack of help - meant I got worse rather than better." (Beat, 2013)

Challenges for Us Health Prof's

- People trying to make a clean break: doing their best & often with little experience of advocating for themselves / navigating healthcare
  - Some with a long history and prior (-ve) treatment
  - Some struggling in the face of relapse
  - Some only just beginning to realise that something is wrong
  - Some determined to cope by ignoring what's wrong
  - Diagnostic instability & incomplete pictures
- Doing our best when no one ever *actually* wants to tell a GP, nurse, HCP or receptionist that they have an eating disorder



Challenges for Students

Waiting time for treatment naïve students (n = 63)	n	%
Waited more than 2 months	32	51%
Waited more than 3 months	26	41%
Waited more than 18 weeks	19	30 %
Waited 6 months or more	17	27 %

Did you / are you experiencing difficulties accessing treatment (n = 183)	n	%
Yes	126	69 %
No	35	31 %

Beat, 2013

Challenges for Us Health Prof's

The course and risks associated with your patients' EDs will be fluctuating: Some will be in mortal danger; many will be unwell; most will be in substantial distress

- Places in formal treatment are limited; out-of-hours provision remains rare
- Treatment seeking students may only be available sporadically and often only for 30weeks of the year
- Recommended therapies: 3months to 1year, weekly sessions & daily effort; *recovery takes longer*
- CBT-E is of limited benefit for 50% *and it's incredibly hard work*
- Not every at-risk student seeks treatment
- Sometimes we feel *really annoyed* with our patients! …And sometimes we feel *really afraid for them.*

III: Rising to the Challenge

Responding as a health professional…

…Receptionist, administrator, HCA, nurse or doctor we all have a role to play

Managing the meeting

Screening

- Screening questions (NICE, 2004)
  - "Do you worry excessively about your weight?"
  - "Do you think you have an eating problem?"
  - The SCOFF: a simple 5 item screening tool (see appendix)
- Key target groups (NICE, 2004)
  - Young women with low BMI; Children with poor growth
  - Those of normal weight consulting about weight concerns
  - Menstrual disturbance/amenorrhoea
  - Signs of vomiting/starvation
  - Gastrointestinal symptoms
  - Non-adherent diabetics
  - \+ minority communities
  - \+ recurrent gym injuries

Managing mixed feelings…

- Explore and acknowledge his/her concerns – be curious
- Slow down, take the heat out, plan for the long game
- Assume ambivalence: aspects of the ED will be valued
- Discuss and look round the options: *"What has helped in the past?"* - what could treatment/change look like?
- Expect self-blame: *"None of this is your fault but - unfortunately - it is your responsibility, so it's good you're here"*
- No change is an option… (but risk management is not optional)
- Resist taking over, but you may have to say*: "I do need to weigh you and take some blood, what's the easiest way?"*
- Acknowledge: *"there is no nice way out of this"*

Facilitating Change

- Emphasise his/her responsibility and support self efficacy: *"So how are you going to manage this? …how can I help you in this?"*
- No change is an option & acknowledging it sometimes has surprising effects: *"but I can't stay as I am"*
- Develop discrepancy: *"on the one hand you are afraid to stop dieting but on the other hand you think it might be making things worse"*
- Resist taking over, help him/her make his/her own plans
- Offer a menu of options and allow processing time
- What could s/he do between now and next time? (tiny self-help steps, make a change however small?)
- Balance your duty of care with efforts to engage and respect for your patient's choices and confidentiality

Supporting self-efficacy

- Managing overwhelm: one step at a time
- Explaining what the options are and how local services work
- Focusing on what the patient is doing to manage (not on what they aren't)
- Looking for & emphasising variability: times when they don't do the ED
- Acknowledging that it's hard work: feelings are irrefutable – be seen to hear them!
- Encouraging patients to identify their own needs and requirements
- Offering another appointment in a few weeks: *"to check-in and see how things are going"*

Avoiding Arguments

This really isn't your problem...

- Positioning yourself as an ally
- Roll with resistance: what might be possible?
- "What" often raises less defense than "why"
- Apologising doesn't mean accepting culpability
- Externalising: "what does the ED make you do"
- Re-framing: how else might the situation be viewed, what went right in all that *appeared* to have gone wrong?
- Reflecting on the process: *"it seems like I'm becoming the enemy…"*
- Being clear about what is and is not negotiable

Managing Risk: The GP-Patient Partnership

Treatment services rely on general practice to manage the ongoing physical health of patients:
Only you have the knowledge and skills

- Show that you think this is serious
- Monitor medical condition & weight
- Emphasise that this is his/her dilemma & his/her responsibility (& so means no need to argue)
- Help him/her make plans (not your plan)... but realistic ones and with time and safety boundaries
- What is *non-negotiable?*

Managing Risk: Non-Negotiables

- **Clear statements about what is, and is not manageable within the current care arrangements and the implications of non-adherence**
  - Enable "firm empathy": being a supporter and a resource without being a 'collaborator'
  - Minimise surprises - maximise patient autonomy
  - Ensure risks are effectively managed: they protect you / your service but, most importantly, they protect your patient
- **Being clear, honest, consistent & ready to explain what is & is not negotiable *up front* puts the patient in charge of his/her health**
- **Non-negotiables might include agreements about:**
  - Ongoing health monitoring (e.g. bloods and (blinded) scaled weight monitoring)
  - Liaison with other services (e.g. counseling), University departments, NHS, etc
  - Scaled weight / BMI limits / rapid changes
  - Self injury, suicidal and other risk behaviours

…What is your *bottom line*?

Managing Risk: Red Flags

- Rapid weight loss (≥ 0.5kg/week) or a BMI ≤13
- Daily vomiting / laxative/diet pill misuse / compensatory exercise
- Fluid restriction / severe dehydration
- Total food avoidance
- Low blood potassium
- ECG changes / Cardiac symptoms (e.g. P&Ns, chest pain)
- Low blood pressure & postural drop
- Fainting / weakness
- Hypothermia
- Skin Breakdown
- Oedema
- Unable to achieve Squat and Sit Up tests
- Active suicidal ideation (thoughts/images, intent, means & plan)

Managing Risk: When the partnership isn't working

People with EDs can appear deceptively well

If risks are escalating / the boundaries aren't holding / or it just doesn't *feel right*:

- Acknowledge your duty of care
- Act decisively if necessary
- Trust your clinical judgement, not patient reassurance
- Consult with your local ED service / Refer

Anne's tips

- Being at a healthy weight doesn't mean being better
- Recovery is a terrifying prospect not just because of what it involves but because of what it might mean
- Beware encouragement/incentives
- Eating doesn't make things better in the short term it makes them a whole lot worse!
- Don't deny the terror of eating
- Do collaborate but don't say you know what it's like
- Hold the hope
- Don't assume: If you don't understand then say so

Where we've been:

- Brief introduction to eating disorders: diagnoses and lived experience.
- Voiced the dilemma facing students and the challenge for us as health professionals
- Explored professional responses: *Whatever* our roles

Thank you, for listening and for your commitment to people with eating disorders

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More: Things to consider (i)

You

- What might you need in order to be better able to support people with eating disorders?
- Do you need help to manage <u>your</u> eating, or with problems associated with shape, weight and food?
- What opportunities might there be for you to support people with eating disorders within your role at work?
- Would you find it useful to do some research on services or treatment needs? E.g. a practice audit, a local service mapping exercise…
- Would you like more training, perhaps even to train as a CBT therapist? (pt time, 1yr)

More: Things to consider (ii)

Your day to day work

- Leaving the responsibility for change with the patient
- Chances are you don't know most of your students with EDs
- Many students with EDs are not White / British / female / middle-class / heterosexual / underweight / transgendered…but some are!
- The merits of curiosity: Most people will talk to us about most things if we approach the conversation in the right way
- Asking a patient if they think they might have a problem with food
- Holding hope for change
- Supporting people to help themselves
- Non-negotiables: What is your bottom line?

More: Things to consider (iii)

Your Service

- Most treatment services *RELY* on primary care to manage patients' physical health
- Books on prescription / copies of a self-help programme / licences for an on-line treatment
- A basic info sheet on services & resources
- Inviting your local ED service in & making a personal link
- Do you need a poster in your waiting room?
- Could you play you awareness-raising videos in your waiting room?

More: Things to consider (iv)

Service Development

- A dedicated (?nursing?) support & monitoring session
- Buying in, or arranging your own, study day
- Outreach
- Case pick up on registration
- Practice lead for EDs
- Hosting a clinic run by your local ED service
- Developing/supporting a student-run group
- A Student Health Association Special Interest Group
- Holding your CCG to account for local ED service provision: is it NICE compliant, does it meet the needs of students?

More: Screening: The SCOFF

- S Do you make yourself **S**ick because you feel uncomfortably full?
- C Do you worry that you have lost **C**ontrol over how much you eat?
- O Have you recently lost more than **O**ne stone (~ 14lbs / 6kg) in a 3 month period?
- F Do you believe yourself to be **F**at when others say you are too thin?
- F Would you say that **F**ood dominates your life?

- Sensitivity of 100% for anorexia and bulimia (ALL $CI^{95\%}$ = 96.9% - 100%; BN $CI^{95\%}$ = 92.6% -100%; AN $CI^{95\%}$ = 94.7% - 100%)
- Specificity of 87.5% ($CI^{95\%}$ 79.2% - 93.4%) for controls; False positive rate (12.5%) is the trade off for high sensitivity

Morgan, J. F., F. Reid and J. H. Lacey. (1999). The SCOFF questionnaire: assessment of a new screening tool for eating disorders. *BMJ.* 319: 1467-1468.

More: Resources

BAPEN, Malnutrition Advisory Group, Malnutrition Universal Screening Tool (MUST)
bapen.org.uk/screening-for-malnutrition/must/must-toolkit/the-must-itself
Beat (formerly The ED Association), message boards, posters, leaflets & more:
b-eat.co.uk
Centre for Clinical Interventions, self help workbooks on EDs, body image & more:
cci.health.wa.gov.au/resources/consumers.cfm
Health Talk Online, read, watch and hear young people's experiences:
healthtalkonline.org/young-peoples-experiences/eatingdisorders/overview
****Institute of Psychiatry** at Kings College London, leaflets, prof guidance, links & more:
kcl.ac.uk/iop/depts/pm/research/eatingdisorders/
MARSIPAN Guideline 2010, management of really sick patients:
rcpsych.ac.uk/files/pdfversion/cr162.pdf
NICE Clinical Guideline, eating disorders:
guidance.nice.org.uk/CG9
NICE Clinical Knowledge Summary, eating disorders:
cks.nice.org.uk/eating-disorders
Royal College of Psychiatry, leaflets, guidance & more:
rcpsych.ac.uk/members/sections/eatingdisorders.aspx
Student Minds, a charity advocating for student mental health and supporting support groups:
studentminds.org.uk

** includes excellent resource on medical monitoring and assessment

More: Download and display for free from the Beat website…

You'll also find an A4 2pp leaflet available for download too

Beat, the UK's leading charity supporting anyone affected by eating disorders or difficulties with food, weight and shape

Help for adults
Helpline: 0845 634 1414
Email: help@b-eat.co.uk

Help for young people
Youthline: 0845 634 7650
Email: fyp@b-eat.co.uk
Text: 07786 201820

Online support including information, message boards and online support groups

Beat Network of Self Help and Support Groups across the UK

HelpFinder online directory of eating disorder service providers

Training and resources for health and social care professionals and schools

www.b-eat.co.uk

beat
beating eating disorders

What do strangers think of you?

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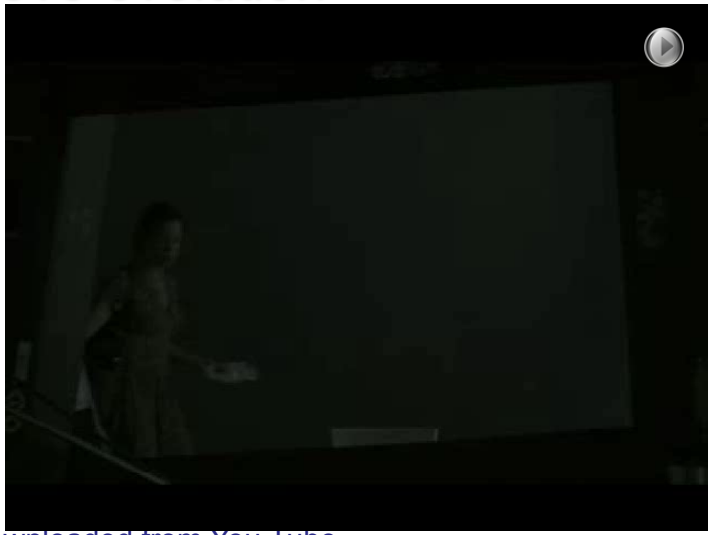
Dove evolution



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10 things you need to know

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