20/10/22 Living With Anorexia Nervosa - Derby Medical Society Meeting

20 October 2022
19:15

Living with Anorexia Nervosa   Dr Larry Higgs and Jenny Higgs (interview recording)

Key points:
- Anorexia nervosa is a complicated disorder which may *present* as a preoccupation with food and weight loss, but eating disorders are a trauma response/psychological issue: weight loss is a *symptom.* As such, BMI is a poor measure of severity.
- Anorexia nervosa has a massive impact on quality of life (for both the patient and their family) and has very high mortality rates. Complete recovery once established is unusual.
- Healthcare professionals should remain aware of presenting features of anorexia (and other eating disorders) and should discuss signs and symptoms clearly but sensitively with patients: believe those who seek help and treat patients as people not numbers.

Features and diagnosis of Anorexia Nervosa, relevant guidelines, discussed.
Preoccupation with food
Male:female ratio
When to suspect an eating disorder:
- When it's suggested by family
- Rapid weight loss/faltering growth
- Social withdrawal
- Chronic illnesses out of control
- Electrolyte/other GI symptoms unexplained
- Any age
- Covert: difference in onset and presentation
- Associated with some sports/modelling/dance

Screening tools, e.g. SCOFF
For physical assessment, follow MARZIPAN guidelines
Need for psychological assessment - psychiatric comorbidity, suicide/sh risk
Refer ASAP, await specialist review. Consider impact on medications. Charities: Beat, Mind.
For GPs: alert on record
Advice: NB diuretics do not reduce calorie absorption
LARCs (ideally mirena)
Pregnancy: safeguarding concerns, risk.
Impact on families: need for support.
Low index of suspicion for admitting: can be unstable (weight loss >1kg/week, refeeding risk, bradycardia, hypothermia, ill health, electrolyte imbalance, lack of support at home!)
Causes of death in patients with eating disorders:
- Electrolyte disturbance
- Cardiomyopathy
- Long QT
- Refeeding syndrome
- Misadventure

Highest mortality rate of any psychiatric disorder
BMI a poor indicator of severity
Full recovery in established eating disorders is unusual

Recording of interview with wife (now age 42, 30 weeks pregnant):

First felt need to be thinner when age 8, wanted to disappear (to avoid sexual abuse from brother)
Never fully recovered, but managed: better during pregnancy, but constant need to restrict when not pregnant
Grew up in Surrey, high achiever. Pushed by family, competitive swimming. Guides, karate, babysitting, did everything to avoid home.
Self-esteem low when young - didn't have many friends, didn't like self. Felt dirty because of abuse at home.
When restricting, felt clean and controlled (in midst of chaos of/lack of control in general life).
Numbers game - how much she weighed, trying to reach next goal post. Felt she could make herself a better person.
Help-seeking: guide leaders had flagged issues to parents, mum brushed off. But age 18 mum saw her getting changed and realised how underweight she was, got GP appointment.
When mum out of room, confessed regarding food restriction and laxative use. St George's eating disorders unit - long weight. But went private, 2 admissions at The Priory before willing to work with staff - not the right time for her.
Noted that the GP took things seriously.
Freedom of university: started to relapse. Went to GP, who pooh-poohed it ("good to look after self", not taken seriously - this was a green flag for her to continue).
Went back with Larry and had lost more weight, but weight "not low enough to warrant treatment". BMI >15
At BMI 15, so entrenched in anorexia that recovery/engagement was so much harder. Firefighting, dealing with physical problems over the eating disorder.
At the time, she was training as a doctor. Eating cucumber and carrot sticks, taking laxatives. Faint, experiencing diarrhoea during clinical placement.
Eventually took a sabbatical at the end of 4th year (obs and gynae elective), but tribunal meeting required for returning to course so decided to abandon medical career and starve instead because that was what she was "good at", enhanced feelings of failure.
Bought diuretics online, long walks, restricted food further. Emaciated, but unable to see this at the time, still felt she took up too much space.
Worst experience ever had - many admissions for hypokalaemia (once 1.5 so central line attempted in A&E, caused pneumothorax). Long time on ward, chest drain. On morning of planned discharge, fainted and hit head (hadn't eaten), subarachnoid haemorrhage. Lost several days' memory. Came to on neuro ward, which was nastier than resp ward, had expressive dysphasia. First time experiencing severe impact from anorexia.
Even off laxatives, struggled with diuretics (furosemide). Repeated hypokalaemic episodes, IV potassium admissions (in and out, nasty cycle).
Wards made her feel like an attention-seeking loser.
Couldn't let go of the control.
Furosemide - 1000 40mg tablets in a week (ordered online) - shameful secret, knew it was bad but felt everything would be fine if she was thinner. Less puffiness = thinner = safer
If no furosemide, had massive rebound fluid retention and associated with panic/distraught state due to loss of control.
Best things health professionals have done?

- Being believed when seeking help, no minimisation based on weight or perceived symptoms: if someone is seeking help for disordered eating, amount of weight loss doesn't actually matter. It is a problem and needs treating. Listening and acknowledging. BMI limit is harmful, bringing weight into it makes it a competition with self/others.
- Having someone listen who wants to help makes a massive difference
- Phrases:
    - Anything not related to weight: eating disorders are a trauma response/psychological issue, weight loss is the symptom.

    - Treating patient as a person rather than a set of numbers
- Resources:
    - Beat meetings, weekly support chats (not allowed to discuss numbers, only feelings)
    - Beat helplines (NB: underfunded)
    - NB: Pro-ana websites can be very harmful. Clamped down on, but it's still online, e.g. through tiktok.

Recent changes - calories on menus prevents her from eating out, not feeling safe.
Effect on being a parent: anxiety around growth scans (baby's weight gain), struggling with children's weight and wanting to support but not pass on eating disorder behaviours. Feeling children's weight and eating habits reflect directly on her.
Drawing attention: wanting to disappear/reduce self, any flesh is too much.

Questions:
Dave: asked regarding relationship with Jenny and Larry and healthcare professionals.
Problems with service structure and basis in weight and BMI. Is there a way to help the patient despite this? Good news: services are moving in the right direction over the last 15 years. Referrals accepted for BMI 20, now just part of the process rather than a strict cut-off.
NB: chronic eating disorder patients' metabolisms will become hypersensitive to starvation. Therefore lethargy, slow metabolism, may contribute to slower weight loss
Stuart: at what level are EDs considered psychotic disorders/treated with antipsychotics, use of canine friends!!
Christopher: anorexia/eating disorder history over the last ~60 years. Emergence related to changing relationship with food. Abundance and variety of food, place of food in society (related to pleasure) has changed significantly. Previously 'ate what you got'. What's *not* new is the psychiatric disorder related to trauma/loss of control as needing to find control - food and body shape as a culprit for something to be controlled. Can spill into wanting more medical treatment: TPN, catheters, lines, etc.
Andy Cole: how to give patients permission to confess their secretive behaviours? Most helpful professional tip from Larry is having own personal experience - knowing what *can* happen and directly asking. Making it easy to bring up! Listening attitude, open questions, posture etc.
Discussed importance of catching early, before impact on weight.
Helen Lever: what responsibility do medical schools bear for students with eating disorders? Attitude of medical school to push her aside was unhelpful. Relapse risk for junior doctors (lack of control).
Current news: how much should parents be told about risk to their >18 children? Suicidal ideation/eating disorder.
Guidelines for the family: how to get through to the patient? Be supportive, non-judgemental, take a step back. Occasionally discuss/confront, but ultimately recognise that you can't stop people from doing what they will do, as this furthers loss of control. Don't try to control/stop. Listen, don't judge.