

# Anorexia and the Court of Protection



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# Caselaw

## Table of reported cases

- Increasing in frequency
- S.15 declarations that P lacks capacity to conduct proceedings and to make decisions about treatment for anorexia including provision of nutrition and hydration
- S.16 decisions:
  - Forced feeding is not in P's best interests
  - A palliative approach is in P's best interests
- And, endorsement of decision not to deploy the MHA

# Familiar questions

- Does it make sense to have litigation capacity and not subject-matter capacity?
- Is it possible to have anorexia and subject-matter capacity?



# New questions

- Is there such a thing as ‘terminal anorexia’?
- Should Trusts ever withdraw medical services from patients with anorexia?
- What is the range of views among psychiatrists on these questions?
- Is there a postcode lottery with regard to treatment and approach?

# Questions from lawyers to clinicians 1

- Is there evidence that discharge from services can help by restoring control to P?
- What options are there for treatment of severe and enduring anorexia?
- Are there new or alternative treatments?
- Are there factors that indicate that palliative care might be more or less likely to be appropriate?
- Age, duration of illness, types of treatment attempted, response to treatment, co-morbidities, risk of refeeding given BMI?

## Questions from lawyers to clinicians 2

- What is poor practice in relation to ED care and how can lawyers spot it?
- What can lawyers do if there is no SEDU willing to accept P? What alternative care plans are there?
- How should the court treat assertions by P that they do not want to die but cannot bear forced feeding? Or that they believe that regaining control of decision-making will help them improve?



## Life and death decisions:

Treatment futility & palliative care controversy in anorexia nervosa and other eating disorders – relevant to CoP

Agnes Ayton, MD FRCPsych, MMedSc MSc  
Consultant Psychiatrist, Oxford Health FT  
Immediate Past Chair of the Faculty of Eating Disorders,  
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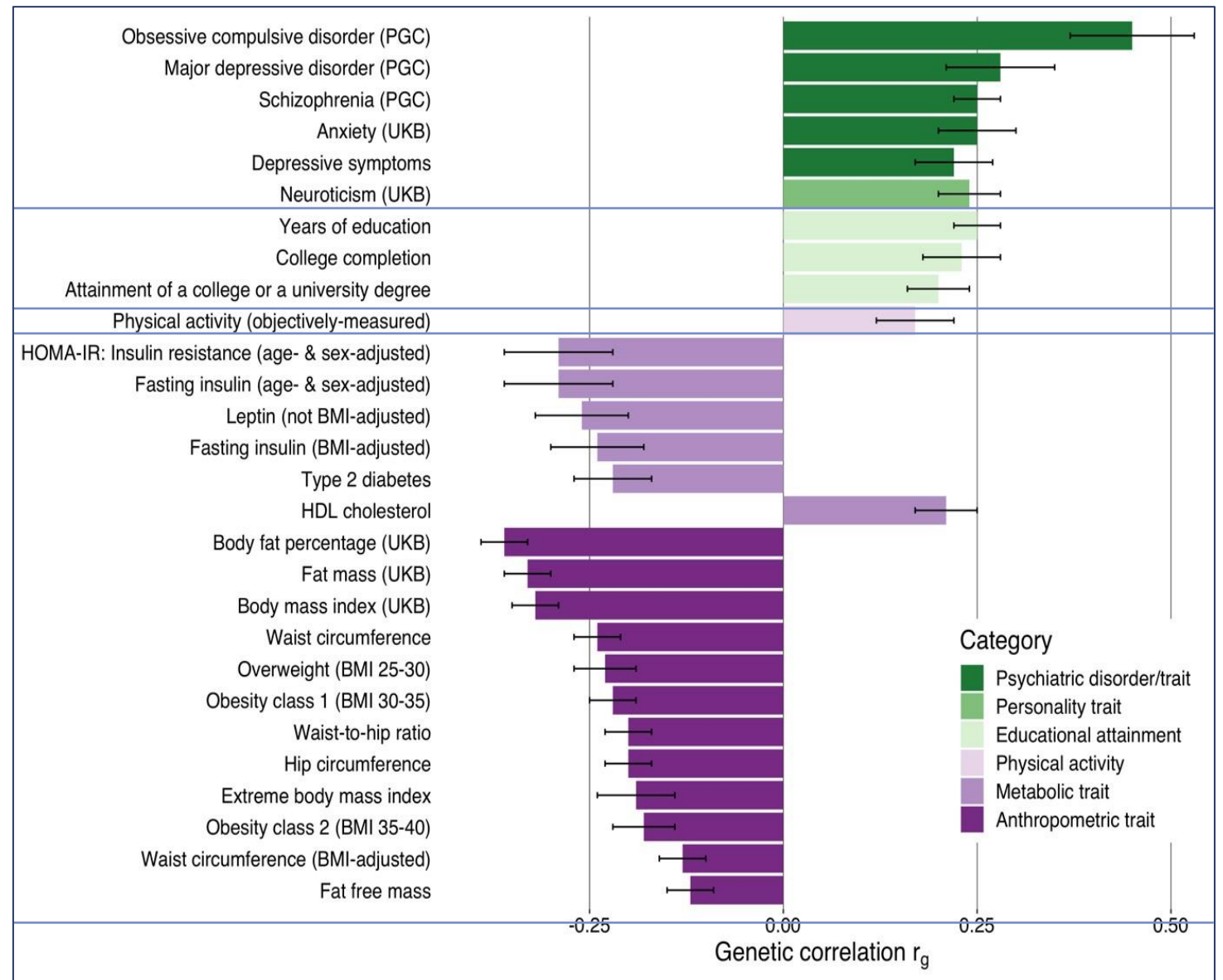
# Key points

- **Anorexia nervosa is a mental disorder and NOT a choice**
- **MHA vs MCA**
  - Compulsory treatment can be lifesaving and does not need to be coercive.
  - No evidence that compulsory treatment is harmful – if therapeutic relationship is maintained
- **Things change**
  - Terminal Anorexia: No crystal ball (or biomarkers)
  - Qualitative research: patients change their priorities with treatment
  - Long term follow-up studies
  - Clinical experience
  - Treatment progress
- **PHSO (2017 & 2023)**
  - Underfunding of services
  - Insufficient medical training
  - Variations in practices



# AN biology:

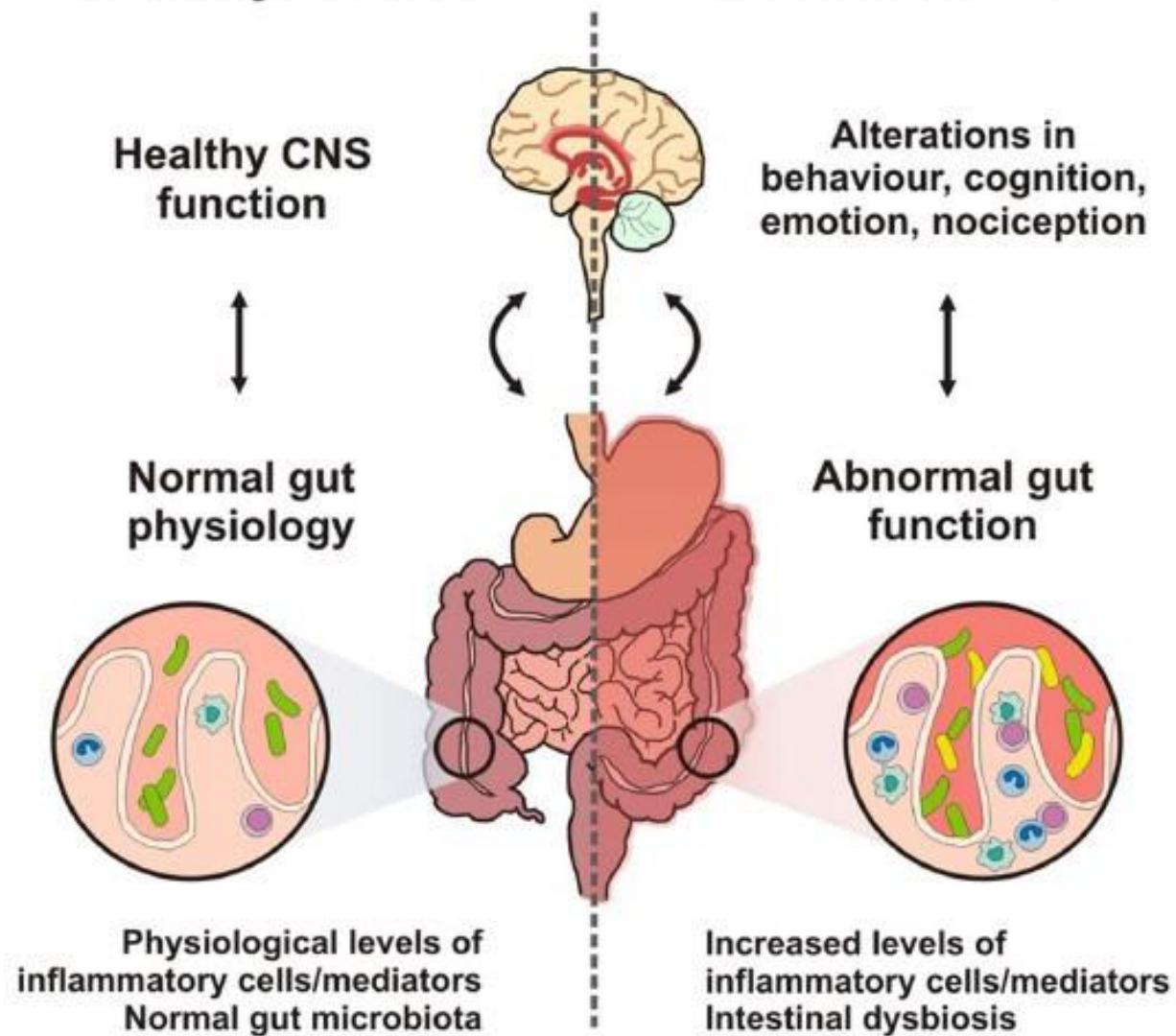
- AN is 56% genetic
- Age of onset: ~18ys
- Biology is not fully understood
- Multimorbidity is common
- **MHA applies**
- Mortality risk is related to no treatment



(Watson et al., 2019)

## Healthy status

## Stress/disease



Inflammatory  
sensitization

# Malnutrition maintains the ED pathology

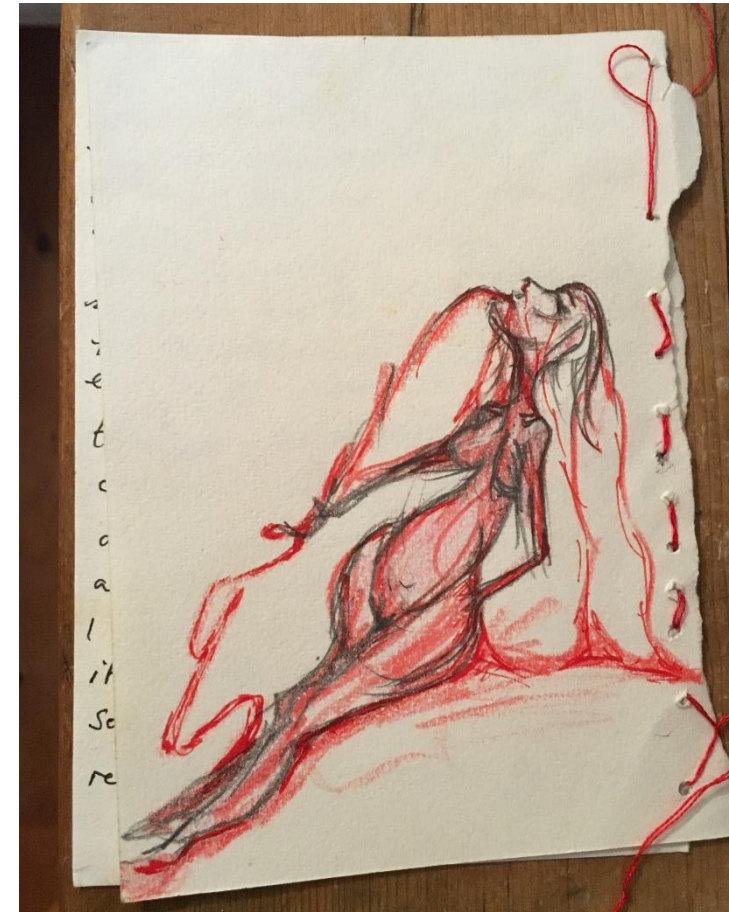
- Increased stress hormones
- Normalisation of BMI is a predictor of good outcomes
  - Neuroimaging studies: the brain atrophy is reversible
- Mean discharge BMI in the UK:
  - Treatment as usual: 17 (15% 1-year remission)
  - Integrated-CBTE: 20 (70% 1-year remission)
- Qualitative work:
  - Patients views and priorities change with weight restoration

# Emotional suffering in AN

*"I hate eating these foods and seeing my weight going up. I cannot feel safe most of the time. It is life destroying and every day I always feel like I am doing the wrong thing, being pushed to every meal with no choice and having to accept that and hating myself even more. And the cycle continues, time keeps going and it is like jumping out of plane every minute of the day. It feels like hell.*

*Tolerating it is painful, it gets to the extreme where I have dark thoughts that I rather die than deal with the severity of the illness, the process ahead and the day-to-day existence I have.*

*It is honestly killing me. Just going round in circles."*



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# Treatment matters

## Compulsory treatment ≠ Coercion



# Treatment futility and TA

- What is "Terminal Anorexia"?
  - 3 cases
  - 30 years old?
  - Wants to die?
  - Had "high quality treatment"?
  - MAID
- Critique:
  - International outcry by patients & experts
  - Controversy within the field
- Can we do better?

<https://citations.springernature.com/item?doi=10.1186/s40337-022-00548-3>

CORRESPONDENCE

Open Access

First, do no harm: the proposed definition of "terminal anorexia" is fraught with danger for vulnerable individuals

Megan Riddle<sup>1</sup>, Anne Marie O'Melia<sup>2</sup> and Maryrose Bauschka<sup>1,4\*</sup>

Received: 9 January 2023 | Revised: 24 March 2023 | Accepted: 25 March 2023  
DOI: 10.1002/eat.23957

FORUM

International Journal of  
**EATING DISORDERS** WILEY

Terminal anorexia nervosa cannot currently be identified

Scott J. Crow MD<sup>1,2</sup>

COMMENT

Open Access

'Terminal anorexia': a lived experience perspective on the proposed criteria

Alykhan Asaria<sup>1\*</sup>

CORRESPONDENCE

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Terminal anorexia nervosa is a dangerous term: it cannot, and should not, be defined

Angela S. Guarda<sup>1\*</sup>, Annette Hanson<sup>2</sup>, Philip Mehler<sup>3</sup> and Patricia Westmoreland<sup>4</sup>

CORRESPONDENCE

Open Access

Inaccessibility of care and inequitable conceptions of suffering: a collective response to the construction of "terminal" anorexia nervosa

Sam L. Sharpe<sup>1\*</sup>, Marissa Adams<sup>1</sup>, Emil K. Smith<sup>1</sup>, Bek Urban<sup>1</sup> and Scout Silverstein<sup>1</sup>



Untreatable or unable to treat? Creating more effective and accessible treatment for long-standing and severe eating disorders

James Downs, Agnes Aytton, Lorna Collins, Suzanne Baker, Helen Missen, Ali Ibrahim

The evidence base for the treatment of severe eating disorders is limited. In addition to improving access to early intervention, there is a need to develop more effective treatments for complex presentations of eating disorders. For

Guest Editorial

From awareness to action: an urgent call to reduce mortality and improve outcomes in eating disorders

Agnes Aytton, Ali Ibrahim, James Downs, Suzanne Baker, Ashish Kumar, Hope Virgo and Jerome Breen



# Life threatening $\neq$ Terminal

- Treatment matters



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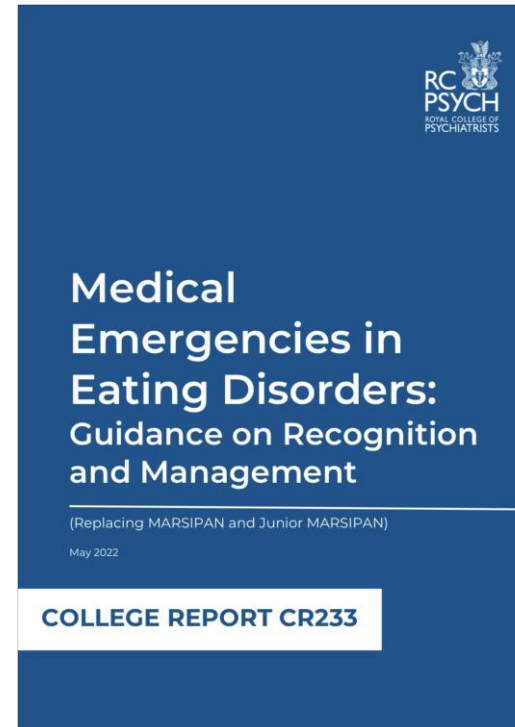
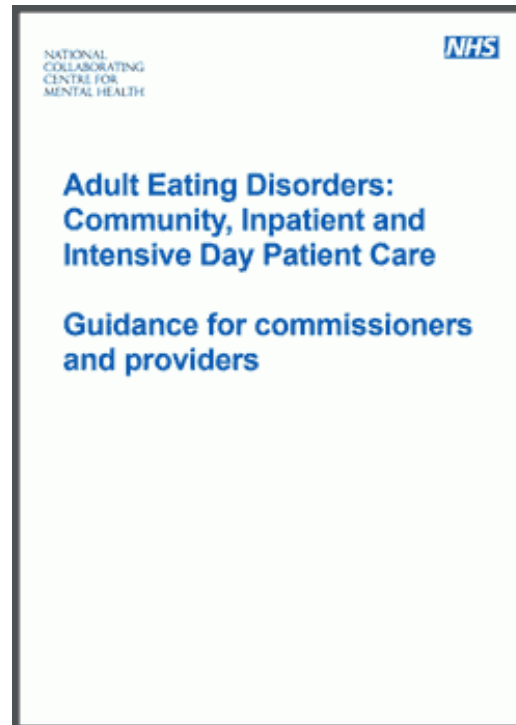
© OMI 00278815.jpg Date Taken: 31/07/2015



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- People's wishes change (Tan, Stewart, Fitzpatrick, & Hope, 2010)
- Malnutrition is reversible

# National drivers for services



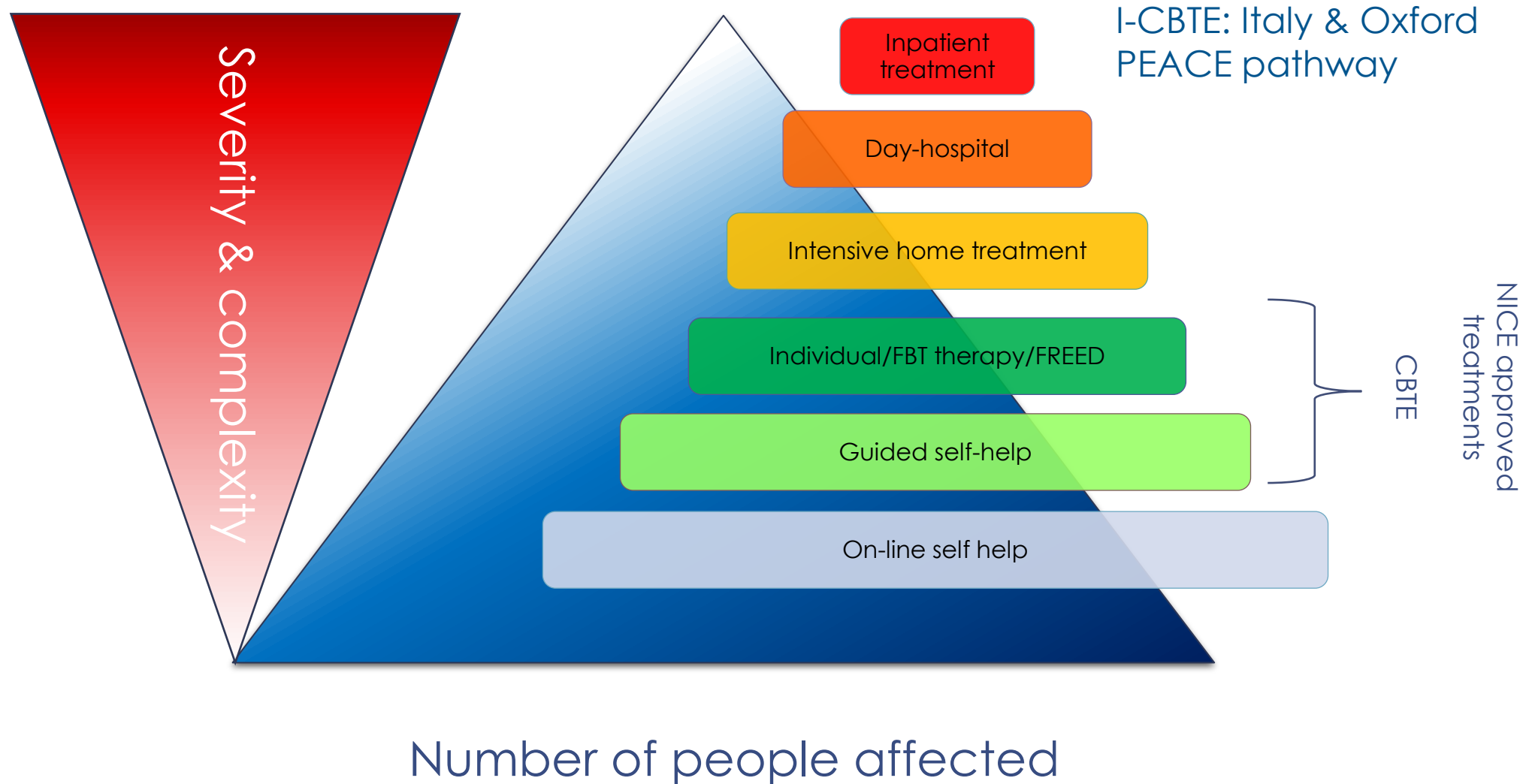
- SIGN
- NICE quality standards
- CAMHS Access and waiting times
- Welsh and Scottish reviews
- LTP

- Inadequate funding to implement guidance

<https://www.ombudsman.org.uk/news-and-blog/news/urgent-action-needed-prevent-eating-disorder-deaths>



# Treatment hierarchy vs. evidence in ED



Behaviourism

Motivational theory

ND

Metabolic science

Psychoanalysis

Systems theory

CBT-E

MANTRA

Genetics

1930s: Bed rest & weight restoration for anorexia nervosa



TAU

1970s: Gerard Russell: 1st SEDU



1990s: Christopher Fairburn: CBTE

2000s: Riccardo Dalle Grave develops Intensive CBTE

I-CBTE



2020s: genetics highlighting complexity, technological advancements



1950s: Operant conditioning

1980s: Motivational theory

1990s FBT for YP

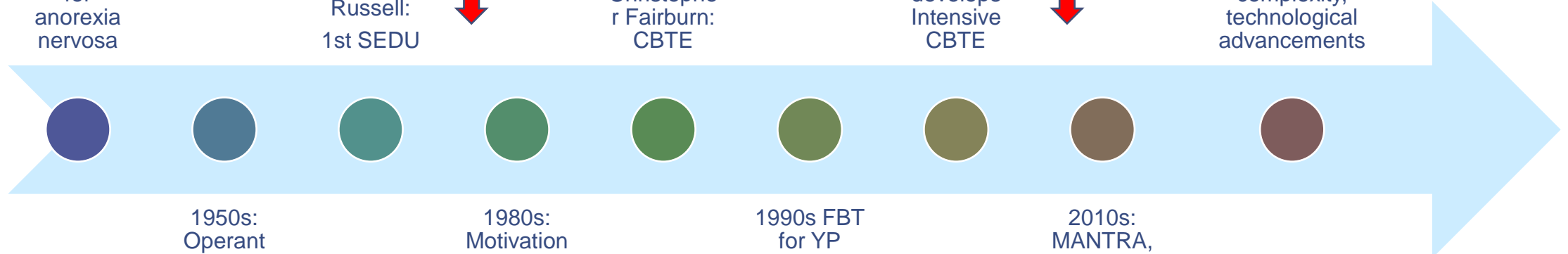
2010s: MANTRA, PEACE, SEED FREED

2004 NICE

2017 NICE

2008 MARSIPAN

2022 SIGN



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Q&A